



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

MOVING TO INDEPENDENT CHOICES:

The Implementation of the Cash and Counseling Demonstration in Arkansas

May 2002

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TABLE OF CONTENTS

	<u>Page</u>
ACKNOWLEDGMENTS	v
EXECUTIVE SUMMARY	vi
I. INTRODUCTION	1
A. Public Personal Assistance Programs in the United States	2
B. Traditional and Consumer-Directed Models of Care	3
1. Traditional Model	3
2. Consumer-Directed Model	3
3. Cash Benefit Programs	5
4. Possible Advantages and Disadvantages of Cash and Counseling	5
C. Cash and Counseling Demonstration	6
D. Design of the Evaluation	8
1. Evaluation of Impacts	8
2. Process Analysis	9
E. Guide to this Report	11
II. DESIGNING INDEPENDENT CHOICES: ISSUES AND DECISIONS	13
A. Goals and Perceptions	14
1. Goals for the Cash and Counseling Program in Arkansas	14
2. Reaction of Stakeholders	15
B. Design Issues and Decisions	18
1. Eligibility and Appropriateness	18
2. Outreach and Enrollment	19
3. Planning the Uses of the Cash Benefit	21
4. Amount of Benefit	22
5. Counseling and Fiscal Services	24
III. COUNSELING/FISCAL AGENCIES	27
A. The Selection Process	27

B.	The Counseling/Fiscal Agencies	28
C.	Quality Assurance	29
1.	Training and Technical Assistance	29
2.	Standards and Monitoring	30
D.	Organization of Counseling/Fiscal Staff	30
IV.	OUTREACH: COMMUNITY INFORMATION AND MARKETING	33
A.	Local Community Information Campaign	33
B.	Centralized Marketing Effort	36
C.	Lessons About Outreach	38
V.	ENROLLMENT	40
A.	The Enrollment Process in Arkansas	40
1.	Initial Interest and Eligibility	40
2.	Enrollment	41
B.	Attractive/Unattractive Features of the Cash Program	44
1.	Attractive Features	44
2.	Unattractive Features	45
C.	Lessons Learned	47
1.	Efficiency in Enrollment	47
2.	Information for Decision Making	48
VI.	CASH PLANNING AND MANAGEMENT	50
A.	Developing the Cash Plan	50
1.	Pre-Visit Telephone Call	50
2.	The Initial Training Visit	51
3.	Nonroutine Requests for Uses of Cash	53
B.	Uses of Cash	54
1.	Hiring Workers	55
2.	Other Types of Expenditures from the Cash Benefit	55
3.	Time to Receipt of Cash	54
4.	Changes to the Cash Plan	58
C.	Payments and Taxes	59
1.	Payment	59
2.	Processing Payroll Documents	61

D.	Major Lessons on Cash Planning and Management	62
VII.	REPRESENTATIVES	64
A.	Selection of Representatives	64
B.	Representative Training and Assistance	65
C.	Major Lessons	66
VIII.	CONSUMERS AS EMPLOYERS	68
A.	Counselor Training on Employer Responsibilities	68
1.	Recruiting Workers	69
2.	Hiring, Supervising, and Firing Workers	69
B.	Training Consumers to Manage the Cash Benefit	70
C.	Registries and Peer Support	71
1.	Worker Registry	71
2.	Peer Support	72
D.	Major Lessons	72
IX.	MONITORING TO PREVENT ABUSE AND EXPLOITATION	74
A.	Contact Between Consumers and Counselors	74
1.	Mode and Frequency of Contact	74
2.	Topics of Discussion Between Consumers and Counselors	76
B.	Review of Receipts	76
C.	Consumer Monthly Financial Statements	77
D.	No Abuse of the Cash Benefit by Consumers	78
E.	Exploitation of Consumers	79
1.	External Complaints	79
2.	Counselor Reports of Exploitation	80

X.	LESSONS FROM ARKANSAS	81
A.	Lessons About Developing a Viable, Cost-Neutral Program	81
1.	Was the Cash and Counseling Program Viable in Arkansas?	81
2.	Value of Independent Choices for Those Not Served by the Traditional System	85
3.	What Factors May Have Affected Program Costs and Budget Neutrality?	85
B.	Lessons of Independent Choices	88
1.	Summary of Component-Specific Lessons	88
2.	How Should Counseling and Fiscal Services Be Structured and Paid for?	90
C.	Value of Counseling and Fiscal Services	93
1.	Burden of Restrictions on Uses of Cash	93
2.	Value of Fiscal Services	93
3.	Value of Counseling Services	94
XI.	TOWARD AN ONGOING CASH PROGRAM IN ARKANSAS	95
A.	Introduction	95
B.	Differences in Demonstration and Ongoing Programs	95
	REFERENCES	98
	APPENDIX A. Self-Screening Forms	
	APPENDIX B. Show Cards	

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EXECUTIVE SUMMARY

Consumer direction seeks to provide people with disabilities with more options and greater personal autonomy in determining how best to meet their care needs in a cost-effective manner. Cash and Counseling is one model of consumer-directed personal assistance services (PAS). Under the Cash and Counseling model, eligible people with disabilities receive a cash benefit. In turn, they assume responsibility for arranging and managing services to meet their personal assistance needs. They may hire workers privately and may receive assistance from counselors if they so desire.

The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services are sponsoring a demonstration and evaluation of Cash and Counseling, which includes a National Program Office at the University of Maryland, Center on Aging. The Centers for Medicare & Medicaid Services (CMS) is assisting in the demonstration, primarily with technical assistance and waivers of federal Medicaid regulations. The demonstration has been implemented in three states: Arkansas, Florida, and New Jersey.

This report describes the design and implementation of Arkansas' model of Cash and Counseling--IndependentChoices--and draws lessons from the state's experience. The report is based primarily on in-person interviews conducted with Arkansas state officials, IndependentChoices' program staff, staff of agencies providing counseling and fiscal services under IndependentChoices, staff of agencies providing traditional PAS in Arkansas, and staff of advocate organizations. In this summary, we briefly describe the design and implementation of IndependentChoices, then draw lessons for future Cash and Counseling programs in Arkansas and other states.

The IndependentChoices Program

The solicitation for demonstration proposals provided the basic outline for IndependentChoices. It stipulated that the cash benefit was to be provided in lieu of traditional PAS--provided either under the Medicaid state plan or under a Medicaid waiver--and was to cover a variety of goods and services.

Arkansas chose to "cash out" Medicaid PAS under its state plan but *not* to cash out services provided under a waiver program, ElderChoices, that provides *additional* services (such as homemaker, chore, and respite services) to elderly recipients of state plan services who meet the criteria for nursing home care. The decision not to cash out ElderChoices was made at least in part to avoid increasing opposition to the cash program from providers of traditional services, most importantly, the Arkansas

Department of Health (ADH) and the Area Agencies on Aging (AAAs), which provided the great majority of both state plan and waiver services. Some of the AAAs strongly opposed the cash program.

Arkansas took a direct approach to reach beneficiaries who were eligible for Medicaid PAS and who expressed an interest in participating in the demonstration. Instead of working through providers of traditional personal assistance, the state hired nurses operating out of different regions of the state to conduct a community information campaign and then to enroll interested Medicaid beneficiaries. In addition, centrally located program staff conducted a direct-marketing campaign which included mailings to each beneficiary receiving state plan PAS services.

The state set up a toll-free telephone number for those interested in participating in the demonstration and a database that they used to verify eligibility for Medicaid PAS during the telephone calls. Contact information was transmitted electronically to the regional nursing staff, who telephoned and then visited interested consumers to enroll them in the demonstration. Consumers who wished to participate but who were unable to manage their own services, were allowed to name a family member or friend as a representative to act on their behalf if they were selected for the cash benefit.

The evaluation contractor, Mathematica Policy Research, Inc., randomly assigned half of the demonstration participants to the treatment group to receive the cash benefit and the other half to the control group to receive traditional services.

Arkansas attracted a large number of participants to the cash demonstration (although not as many as the original evaluation design called for). Ultimately, about 2,000 people participated in the demonstration (in the treatment and control groups combined), roughly 10 to 15 percent of the number of PAS recipients annually.

Arkansas based the amount of the cash benefit on the care plan. The amount was based on the current care plan for treatment group members who were already PAS recipients, and the outreach/enrollment nurses developed care plans for those new to PAS. Both types of care plans were cashed out at \$8.00 an hour after “discounting.” Discounting involves multiplying the care plan hours by the ratio of the cost of services actually received to the cost of services listed on the plan of care. It is intended to ensure the budget neutrality of the cash program by taking into account the fact that the amount of services received is generally less than the amount planned, (due, for example, to hospital admission of PAS recipients and insufficient supply of aides). Arkansas developed provider-specific discount rates for current recipients of PAS by comparing care plans and claims for the previous year for random samples of those served by various providers of traditional personal assistance. These provider-specific discount rates ranged from about .70 to .91. A rate of .91 was applied to the care plans of new recipients of personal assistance.

Arkansas drew up a broad list of goods and services covered by the cash benefit and required that consumers develop a plan for uses of the cash benefit before receiving any cash payments. Almost all consumers who received a cash benefit hired a worker with these funds, usually a family member or friend. Although the demonstration waiver permitted hiring of legally liable relatives (spouses and legal guardians of adults), Arkansas chose not to exercise this aspect of the waiver. Some consumers also purchased assistive equipment, personal care supplies, and nonprescription and prescription medications (when these medications were not covered by Medicaid). A few purchased materials to modify their homes, such as lumber for a ramp.

The state contracted with two human services organizations--each of which was to provide both counseling and fiscal services under IndependentChoices. One host organization was a for-profit organization with expertise in rehabilitation services. It became the counseling/fiscal agency for three-quarters of the state. The other host organization was a nonprofit organization providing schooling and supportive services to children and adults of all ages. It became the counseling/fiscal agency for the other quarter of the state. (A contract to provide counseling/fiscal services was also awarded to an AAA, but it withdrew shortly after operations began.)

Under IndependentChoices, counselors had a variety of responsibilities. They visited all treatment group members to help them prepare their initial cash management plans and approved revisions to these plans. The state permitted counselors to authorize the purchase of any good or service on a preapproved list, with review by state staff of any unlisted good or service. Counselors also advised consumers about the nonfiscal responsibilities of an employer, including hiring, training, supervising, and (if necessary) firing workers. In addition, counselors monitored the use of the cash and the condition of the consumer, speaking to consumers by telephone at least monthly and visiting them periodically. Consumers maintained receipts to document the uses of cash (except for discretionary funds to total no more than 10 percent of the benefit), and counselors carefully reviewed these receipts, thereby monitoring the uses of the cash. Also, counselors were responsible for reassessing the care needs of cash recipients every six months (or when events precipitated a change in need) and revising their care plans following reassessment. (The staff of traditional agencies was responsible for reassessing and revising the care plans of the recipients of their services.)

The fiscal services available to consumers under IndependentChoices were provided to them without charge and included preparation of payroll documents (including those pertaining to federal and state payroll taxes and state unemployment insurance) and check-writing and bookkeeping services. Consumers were required to demonstrate sufficient knowledge before assuming payroll responsibilities. Nearly all consumers chose to avail themselves of the fiscal services for payroll documents.

Arkansas paid the counseling/fiscal agencies a monthly management fee for each person assigned to the treatment group, with the amount of the fee reduced after every six-month interval (for two years). The fee was reduced based on the presumption that as a consumer's experience with self-management increased, reliance on counseling support would decrease.

Lessons from IndependentChoices

The procedures developed for IndependentChoices were, on the whole, successful. Arkansas' experience suggests a number of lessons about operating a Cash and Counseling program.

Outreach and Enrollment. Direct mailings to recipients of Medicaid PAS appear to have been the most effective approach to generating participation. Direct mailings are more targeted and can be more precisely worded than newspaper articles and public service announcements. Program staff considered direct mailings more cost-effective than the other marketing techniques because they expended fewer resources responding to inquiries from those who proved ineligible for Medicaid PAS.

The Arkansas experience also suggests that a sizable staff is needed for simultaneous community information and marketing efforts. Arkansas staff mounted a community information campaign, but were unable to maintain this level of effort once enrollment began. Senior state staff mounted the marketing campaign even as they worked to implement the cash program day to day. Arkansas would have needed substantially more staff than it had resources to hire to simultaneously implement major community information, marketing, and enrollment efforts.

Arkansas enhanced the efficiency of the enrollment process by reducing paperwork, smoothing work flow, minimizing travel, and reducing multiple home visits in a given case, almost to the point of eliminating multiple visits. Having family members and friends present at the initial home visit was particularly important to minimizing multiple visits, both because family members and friends were potential representatives and workers and because they could answer questions that the consumer raised after the home visit.

Arkansas learned that the presentation of information was critical during enrollment. Staff had to actively combat the misunderstanding that the cash benefit would be treated as income for the purposes of determining eligibility for means-tested federal programs and determining federal tax liability. Another lesson was the importance of providing information in ways that people of limited reading ability could understand and framing answers to their questions in terms that they found meaningful. The state provided multiple opportunities for oral communication; written materials were insufficient alone.

Attractive Program Features. Program staff reported that consumers found the ability to hire family members to be the single most attractive feature of IndependentChoices. Having a family member as a worker provided consumers with security and peace of mind; they disliked having strangers come into their homes. Moreover, some consumers found it demeaning to have intimate personal assistance provided by a stranger. Other consumers had been dissatisfied with traditional PAS, finding the schedules inflexible or the aides unreliable. In some cases, traditional personal assistance agencies simply had been unable to supply aide services.

Unattractive Program Features. Participation in IndependentChoices was less attractive to ElderChoices participants, according to program staff. Since ElderChoices had not been cashed out, aides from that waiver program would still be coming to consumers' homes. Moreover, consumers participating in both programs often had a majority of their home care hours through ElderChoices, an artifact of a defunct state policy under which the maximum number of hours available under ElderChoices was included in the care plan *before* any PAS hours. As a result, cash benefit levels under IndependentChoices tended to be lower for consumers participating in both programs than for other PAS recipients. Since about a third of state plan PAS recipients also received ElderChoices services, the failure to attract them probably contributed to the difficulty Arkansas had in meeting the sample size targets of the evaluation.

According to program staff, other unattractive features of IndependentChoices included the amount of paperwork required and restrictions on the uses of the cash benefit, especially the restriction on hiring spouses. In addition, IndependentChoices tended to be less attractive to consumers who liked their current personal assistance aide. Random assignment (an artifact of the evaluation) was also an unattractive feature.

Counseling and Fiscal Services. One lesson regarding counseling services is that, for most consumers, quarterly monitoring visits are not necessary. IndependentChoices revised its initial requirement of a quarterly visit (to at least a semiannual visit) because it became clear that most consumers did not need visits quarterly, although a few required very frequent visits in the course of resolving particular problems.

Three major lessons about cash management emerge from IndependentChoices. First, counseling for cash planning is labor intensive--both for development of initial cash management plans and for revision of cash plans as consumers' needs and desires change. Second, counseling and fiscal issues are often closely associated. The issues that counselors address often have fiscal implications, and discussion of fiscal issues often reveals underlying counseling issues. Third, the Arkansas experience shows that most interested consumers--even those with limited formal education--can develop a cash management plan in a few weeks, provided that: they (1) have assistance from counselors, and (2) can identify a worker from among their family members and friends. Although counselors trained consumers to look for a worker in a "widening circle," those who were

not able to identify a family member or friend as a worker reportedly were more apt to disenroll from the demonstration.

There are several possible reasons for the relative lack of success among consumers *without* family members and friends to serve as workers. First, those who hired workers from outside their family and friends did not experience one of the most attractive potential benefits of the cash program--avoiding having strangers come into the home. Second, the wages cash recipients offered may not have been sufficient to attract workers who did not know the consumer personally. Third, Arkansas and its counseling/fiscal agencies did not develop formal referral mechanisms for finding workers, although informal referral mechanisms began to develop relatively late in the demonstration.

In recent years, many traditional agencies have found it difficult to hire enough personal assistance aides to meet the demand. Thus, an important lesson of IndependentChoices is that Cash and Counseling appears to tap a new source of personal assistance workers--family members and friends who were willing to assist a loved one for a relatively low hourly wage but not interested in agency employment. Such family members and friends can help people who were not being served (or who were underserved) by the traditional program.

Another lesson of IndependentChoices is that dividing the responsibilities of the employer between the consumer and the fiscal agent can be successful. Consumers retained responsibility for timely submission of worker time sheets and fulfilled this responsibility successfully on the whole. Agencies were largely successful in implementing fiscal services. Consumers received their cash benefits and monthly statements in a timely way, and workers usually received their paychecks in a timely way.

Except for difficulty in recruiting workers from beyond the circle of family members and friends, consumers satisfactorily fulfilled the nonfiscal responsibilities of employers in hiring, training, supervising, and firing workers. Counselors played a major role in this success--partly by advising consumers and partly by treating consumers as "the boss" and thereby empowering them relative to their representatives, workers, and other family members.

Roughly half of the consumers in IndependentChoices named a representative to help them manage the cash benefit. An important lesson of Arkansas' experience is that representation is successful and a natural extension of the relationships that consumers already have and of the assistance they are already receiving. Under IndependentChoices, consumers who needed a representative generally identified that need themselves and selected their representatives wisely. Representatives almost invariably acted in the best interests of consumers, with family members taking a holistic view of consumers' situation and acting as consumer advocates.

IndependentChoices presents two major lessons with respect to monitoring to prevent abuse of the cash benefit and exploitation of consumers. Requiring receipts to document the uses of cash reportedly was instrumental in preventing the abuse of the cash benefit by empowering consumers and representatives to prevent their family members from using the cash benefit inappropriately. Counselors' careful observation for subtle changes in consumer behavior and a positive approach to correcting problems were key ingredients in preventing almost all exploitation of consumers and quickly resolving the handful of cases that did arise.

Budget Neutrality: Discounting, Counseling/Fiscal Fees, and Reassessment.

Consistent with the federal requirements for the demonstration waiver, IndependentChoices was not expected to be budget neutral immediately. Rather, the cost per recipient per month for the cash program was to be brought in line with the comparable cost for the traditional program over the course of the five-year demonstration waiver. Analysis of the impact of IndependentChoices on costs must await the evaluation's analysis of claims. Nonetheless, this study provides some lessons about discounting, counseling/fiscal fees, and reassessment that should be helpful in designing budget-neutral Cash and Counseling programs.

The appropriate initial discount rates in Arkansas may have depended on two factors that were unknown when the state developed the initial discount rates and that were out of its control. First, the appropriate discount rates may differ from historic rates because the ratio of the cost of services received to the cost of services planned has changed. For example, as the labor market tightened in the full-employment economy of the late 1990s, it may have been harder for traditional agencies to find enough workers to deliver all the hours specified in the care plans. Second, discount rates developed for random samples of *all* PAS recipients may be inappropriate if those who choose to participate in the demonstration differ systematically from other PAS recipients. For example, PAS recipients who were underserved (or not served at all) in the traditional program had a greater incentive to participate in IndependentChoices. Assuming that the care plans of the underserved did not systematically understate their care needs, underservice would be associated with having a smaller fraction of planned care actually delivered (relative to the fraction for PAS recipients in general).

Arkansas' method of payment of counseling/fiscal agencies increased program cost and thus affected budget neutrality. The state paid the counseling/fiscal agencies a monthly fee for each consumer enrolled, regardless of whether the consumer had begun to receive the cash benefit. Consequently, the state incurred costs for *both* traditional services and counseling/fiscal services until a consumer began to receive the cash benefit and traditional services discontinued (or until the consumer disenrolled).

Another factor that may have affected budget neutrality is the possibility of different assessment procedures for treatment and control group members who were new to PAS.

Although the outreach/enrollment nurses assessed and developed care plans for those new to PAS who were interested in the cash program, traditional agencies were not required to honor these care plans. Instead, they may have reassessed new recipients of PAS referred to the control group, which could result in different costs for the treatment and control groups.

Different reassessment procedures may have led to systematically larger amounts of care planned for cash recipients than for recipients of traditional services, and this may have increased the cost of the cash program relative to the traditional program. Faced with a shortage of aides, providers may have tended to avoid increases in the hours of care planned for recipients of traditional personal assistance (even in situations in which an increase was justified). In contrast, counselors may have tended to authorize an increase in care plan hours since the cash program was tapping a different supply of workers--the family members and friends of consumers.

Moreover, under IndependentChoices, the discount rate for care plans following *reassessment* of cash recipients (.91) was more generous, on average, than their initial discount rates (which ranged from .70 to .91). A more generous discount rate at reassessment may have the effect of increasing the cost of the cash program relative to the cost of the traditional program since the amount of the cash benefit would be increased when the reassessment care plan was cashed out.

Structure of IndependentChoices. Four important lessons emerge from the Arkansas experience about structuring a Cash and Counseling program. These lessons pertain to:

1. Combining counseling and fiscal services within an agency
2. Having multiple counseling/fiscal agencies
3. Orientation of host organizations
4. Structure of counseling services

Contractual responsibility for counseling and fiscal services was combined under IndependentChoices. Indeed, the counselors were responsible for some fiscal activities, such as approving timesheets and purchase orders. The state program staff and the counseling/fiscal agencies felt that counseling and fiscal activities are so closely linked that combining them enhances efficiency. However, while day-to-day bookkeeping activities went smoothly, neither of the counseling/fiscal agencies was fiscally sophisticated when implementation began. For example, despite the technical assistance the National Program Office provided, both counseling/fiscal agencies erred initially by failing to refund excess withholding to consumers and workers. Possibly, the requirement that counseling and fiscal services be combined discouraged bids from organizations with more fiscal expertise but little or no human service expertise, as a joint bid would be required in that situation.

Under IndependentChoices, multiple counseling/fiscal agencies served different geographic areas of the state. Having multiple agencies was an important safety net for the cash program. It enabled program operations to proceed smoothly when the state did not receive an acceptable bid for counseling/fiscal services in one region of the state and when the successful bidder for another region dropped out of the cash program early. Simply having multiple agencies is not in itself sufficient to form a safety net; at least one agency must be in a position to expand to cover other regions of the state.

The orientation of host organizations may have been a fundamental strength underlying the successful implementation of the cash program in Arkansas. Neither focused on providing traditional home care. One organization's background was the provision of rehabilitation therapy, and a school was at the heart of the services provided by the other. The orientation of the host organizations (to rehabilitation and to schooling) may have been more consistent with the philosophy of consumer direction than was the orientation of traditional personal assistance agencies.

The successful implementation of IndependentChoices also may partly reflect the way in which the provision of counseling services was structured at the counseling/fiscal agencies. In each of them, counseling was provided primarily by full-time staff members who were responsible only for the cash program. Thus, counselors could focus their attention on implementing IndependentChoices without being distracted by other responsibilities.

Moreover, in both of the counseling/fiscal agencies, counselors initially had separate caseloads, but soon moved to shared caseloads. Shared caseloads are more efficient (reducing telephone tag with consumers and travel time) and allow counselors to apply their particular areas of expertise to address the needs of more consumers.

Agency Cash Flow. Counseling/fiscal agencies experienced serious cash flow problems early, before they had established reasonable caseloads. A simple solution to this problem may be for the state to provide new counseling/fiscal agencies with an up-front payment (to be recouped later).

Value of Counseling and Fiscal Services. The tenet of the Cash and Counseling model that distinguishes it from other models of consumer direction is the provision of services to help consumers manage the cash benefit. Some critics of this model argue that an unfettered allowance (for consumers to spend as they choose) would be preferable, as it is more consistent with the philosophy of consumer direction. Whatever the philosophical merits of an unfettered allowance, most Arkansas consumers seemed to accept the authority of the Medicaid program to impose restrictions on the use of public funds and expected to be asked to show receipts to document their adherence to these restrictions.

The counseling and fiscal services IndependentChoices provided appear to have benefitted consumers. Fiscal services were clearly attractive. Consumers were *not* required to use these services, yet the great majority did so.

The value of counseling services to consumers is more difficult to assess. In general, counselors seem to have empowered consumers, and counselor monitoring and a positive approach to problem solving seem to have been important in preventing exploitation of the consumer and abuse of the cash benefit. Nevertheless, consumers varied greatly in the amount of advice and training they needed from counselors. Some needed little or none, while other consumers needed a great deal of assistance, especially in the weeks and months in which they were developing a cash management plan and hiring workers. Counselors learned not to overwhelm these consumers with materials and information and to focus on what they needed to know. Overall, counseling seems to have been valuable--perhaps essential--to the success of the cash program in Arkansas.

Future Cash Program? Arkansas views a consumer-directed cash program as a valuable part of a package of programs designed to meet the needs of its citizens, and it is working to adopt a slightly revised version of IndependentChoices as a permanent program. At the time of our visit, the major revisions involved (1) cashing out the ElderChoices waiver (as well as the Medicaid state plan services); (2) less emphasis on outreach; (3) greater attention to training consumers to be employers, and (4) revising the payment structure for counseling/fiscal agencies to provide a one-time payment for developing the cash management plan, followed by a fixed monthly payment per cash recipient.

I. INTRODUCTION

The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services (HHS) are sponsoring the demonstration and evaluation of Cash and Counseling. RWJF and ASPE co-funded a National Program Office for the demonstration at the University of Maryland, Center on Aging, and they co-funded the evaluation, while RWJF funded grants to the demonstration states. The demonstration required waivers of federal Medicaid regulation. The Centers for Medicare & Medicaid Services (CMS)--at that time, the Health Care Financing Administration (HCFA)--was responsible for these waivers. CMS took the lead role in developing and implementing the waiver terms and conditions (including budget neutrality), reviewing state demonstration protocols, and ensuring that all aspects of the state demonstrations were operational before they were implemented. This demonstration was implemented in three states: Arkansas, Florida, and New Jersey.¹

Cash and Counseling is one model of consumer-directed personal assistance services (PAS). The goal of Cash and Counseling is to provide people with disabilities with more options and greater personal autonomy in determining how best to meet their long-term needs in a cost-effective manner. Under Cash and Counseling, eligible people with disabilities receive a cash benefit. In turn, they assume responsibility for arranging and managing services to meet their personal assistance needs. They may hire workers privately and may avail themselves of the assistance of counselors if they so desire.

This chapter provides the reader with the background information needed to understand Arkansas' implementation of the Cash and Counseling model, IndependentChoices. Section A provides a brief summary of personal assistance programs in the United States as planning for the Cash and Counseling Demonstration began. Section B provides a brief summary of the models of care being implemented at that time. Readers familiar with these programs and models of care may choose to skip ahead to Section C, which provides a brief description of the design of the Cash and Counseling Demonstration as envisioned by RWJF and ASPE. Section D describes the design of the evaluation, with special emphasis on the methodology for this process analysis. Finally, Section E provides a guide to this report.

¹ For simplicity, we refer to a single Cash and Counseling *Demonstration*. Because each state was expected to design its own demonstration (within the constraints laid down by the funders and federal regulations, including the waiver terms and conditions), the program was originally referred to as the Cash and Counseling *Demonstrations*. However, a single National Program Office provided oversight and guidance to all the states, and a single evaluation contractor was selected. Over time, references to a single "demonstration" supplanted references to multiple "demonstrations."

A. Public Personal Assistance Programs in the United States

People with disabilities often require personal assistance to remain in home and community settings. At the time that planning for the Cash and Counseling Demonstration began, HHS had estimated that more than 25 million children, working-age adults, and elderly people had a substantial limitation in physical, mental, or emotional function and required assistance at some level (Cameron and Firman 1995). Personal assistance was usually defined as assistance with tasks that people would normally do for themselves if they did not have a disability--tasks like personal maintenance and hygiene, mobility, household maintenance, child care, cognitive or life management activities, personal security, and communication (Litvak et al. 1987).

As planning for the Cash and Counseling Demonstration began, several public programs existed to provide personal assistance to people with disabilities. These programs included Medicaid personal care state plan optional benefit programs, Medicaid home- and community-based waiver programs, other programs funded by other federal revenues (for example, the Social Services Block Grant and the Older Americans Act), state general revenues, and local revenues.

The availability of these programs varied by state. Medicaid state plan personal care programs--an optional benefit under federal regulations--had become a major source of public funding for personal assistance services (PAS) by the mid-1990s (Doty et al. 1996; and Litvak and Kennedy 1991). The number of states with Medicaid state plan personal care programs had increased from 17 in 1982 to over 30 in 1996 (Health Care Financing Review *Medicare and Medicaid Statistical Supplement 1996*). While all states had Medicaid home- and community-based waiver programs at that time, these programs tended to be small and targeted to special populations (Litvak and Kennedy 1991).² As a result, Medicaid state plan program expenditures were more important than Medicaid waiver programs as a source of assistance to adults with disabilities. Other federally funded personal assistance programs were limited in size because of funding constraints. The availability of state-funded programs also varied widely. Some states (including California for a number of years) relied heavily on state revenues to provide personal assistance, but more than a third of states did not use any state general revenue funds for this purpose (Justice 1993).

² Arizona did not operate a home- and community-based waiver, but it offered comparable long-term care services under a federal research and demonstration waiver.

B. Traditional and Consumer-Directed Models of Care

The traditional model of PAS and the consumer-directed model are distinct models for providing personal assistance.

1. Traditional Model

As planning for the Cash and Counseling Demonstration began, most personal assistance in the United States was provided within a traditional model of PAS. The traditional model includes case management services to assess need, plan and coordinate services, and supervise personal assistance workers. About half of traditional programs required licensed vendor agencies to provide services, and the other half allowed clients to hire workers, including nonlicensed providers, privately (Litvak et al. 1987). Vendor-provided services and case management tended to limit client choice and control over PAS, as well as to increase the cost of providing personal assistance.

Critics of the traditional model of PAS have long argued that it is not well suited to meet client needs, values, and preferences. They argue that many clients, especially younger people with disabilities, do not want or need case management services. Furthermore, other clients may prefer that friends or family members provide assistance or prefer to seek services other than PAS (such as adult day care) to meet their needs.

By the time that planning for the demonstration began, some PAS programs had fostered client choice by allowing clients to hire, fire, train, and/or supervise workers. Among Medicaid personal care programs, however, the degree to which clients could manage their privately hired workers usually was limited. For example, the worker usually was paid by the program, not the consumer (Cameron and Lagoyda 1997). A survey of 12 Medicaid personal care programs that permitted privately hired workers found that most programs allowed clients to hire and fire their own workers, but only half allowed clients to train their workers, and only a quarter allowed clients to participate in paying their workers (Doty et al. 1996).

2. Consumer-Directed Model

Consumer direction is rooted in the Independent Living Movement, which was originated nearly three decades ago by younger adults with disabilities who sought to lead more fulfilling and independent lives (DeJong 1979; Doty et al. 1996; and Litvak et al. 1987). To achieve greater independence, they struggled to take control of their PAS. The Independent Living Movement coincided with the consumerism movement, which led to the use of the term “consumer-directed” to describe the model of care the movement advocated (DeJong 1979; and Litvak et al. 1987).

Consumer-directed models aim to allow people with disabilities to direct the who, how, and when of service delivery (Litvak et al. 1987). When planning for the Cash and Counseling Demonstration began, the National Institute on Consumer-Directed Home- and Community-Based Care Systems (1996) had defined consumer direction as:

...a philosophy and orientation to the delivery of home- and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction may exist in differing degrees and may span many types of services. It ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services.

The level of consumer control within actual programs falls upon a continuum (National Institute on Consumer-Directed Home- and Community-Based Care Systems 1996; and Doty et al. 1996). An approach to judging where a program falls upon the continuum is to assess to what extent it includes the 10 characteristics of the Independent Living Model (see DeJong and Wenker 1979 and Litvak et al. 1987):

1. No medical supervision is required.
2. The consumer can use privately hired providers.
3. The consumer hires and fires the worker.
4. The consumer pays the worker.
5. The consumer trains the worker.
6. The consumer participates in deciding on the number of hours and type of service he or she requires.
7. The service provided includes catheterization, personal maintenance and hygiene, mobility, and household assistance.
8. The maximum service limit exceeds 20 hours per week.
9. Service is available 24 hours a day, seven days a week.
10. The income limit is greater than 150 percent of the poverty level.

The National Institute on Consumer-Directed Home- and Community-Based Care Systems (1996) proposed a set of broader criteria for assessing the extent to which a program is consumer-directed. These criteria are the (1) ability of consumers to control and direct the delivery of services, (2) variety and type of service delivery options actually available to consumers, (3) availability of appropriate information and support, and (4) ability of consumers to participate in systems design and service allocation.

When planning for the Cash and Counseling Demonstration began, examples of consumer-directed programs in the United States included those in California (the largest in the country), Massachusetts, and Michigan. Each of these programs met 7 to 8 of the 10 characteristics of the Independent Living Model (Litvak et al. 1987).

3. Cash Benefit Programs

In theory, a cash benefit represents a high level of consumer control on the continuum of consumer direction. Yet consumer control can be limited if the cash benefit is restricted (Kane 1996). Restrictions may include limitations on services covered. For example, while some private insurance plans pay cash to people with disabilities, others only cover expenses for a list of authorized services (Cameron and Firman 1995; and Freedman and Kemper 1996). Other restrictions involve who may be hired as workers. Hiring restrictions may include not permitting the hiring of close relatives and requiring that workers have specified credentials or fulfill preemployment training requirements.

When planning for the Cash and Counseling Demonstration began, most cash benefit programs in the United States were small (although the size varied). The Wisconsin Community Options Program is an example of the small programs operating at that time--it targeted only five percent of its caseload (or about 650 people) to receive a case-managed cash benefit; in contrast, the Michigan Home Help Program served more than 30,000 consumers at that time (Cameron and Firman 1995; and National Institute on Consumer-Directed Home and Community-Based Care Systems 1996).

When planning for the demonstration began (as now), federal statute prohibited direct cash payments with Medicaid funds. Thus, in the cash benefit programs then funded under Medicaid, clients did not receive direct cash payments to pay for personal assistance. Instead, states commonly paid wages directly to workers.

4. Possible Advantages and Disadvantages of Cash and Counseling

When planning for the Cash and Counseling Demonstration began, its designers saw payment of a cash benefit as having the potential to give clients the power to purchase services that best fit their long-term care needs and individual values. With cash, clients were expected to design individual service packages. They could purchase traditional case-managed PAS, hire workers privately, make home modifications, purchase equipment, or use adult day care or other home- and community-based services as alternatives to in-home personal assistance (Cameron 1995; and Kane 1996). They were in a better position to arrange for services at times that met their needs. They could also hire their friends and relatives if they believed that doing so was in their best interest. Depending on the level of the cash benefit, the cost of traditional services, and the cost of alternative services, clients might also be able to purchase more hours of services than they received from the traditional program. These changes were seen as having the

potential to increase autonomy, better address unmet needs, and improve satisfaction--changes that might in turn result in improved functioning (Kane 1996).

In addition, at that time, reductions in public expenditures were viewed as being possible, as traditional case management services and administrative functions were eliminated under Cash and Counseling and clients took responsibility for managing their own services. If the cost of providing counseling were less than the cost of these traditional functions, savings would accrue. Savings might also accrue if the cost of paying cash benefits were less than the cost of processing claims. Also, the potential cost to the state of collective bargaining with personal assistance attendant unions and of liability actions against the state was eliminated (see, for example, Jackson 1994; Cameron 1995; Doty 1996; and Flanagan 1994).

At the time the Cash and Counseling Demonstration was being designed, states had relatively little experience with cash benefit programs. Therefore, public officials were concerned about possible abuse of the program. They felt that clients might be exploited by their relatives or workers or might not use their cash benefit for the intended purpose.

Some public officials were also concerned that a cash benefit might create more demand for services (the so-called "woodwork" effect), thus straining available resources.

Finally, there was concern that traditional PAS providers might object to Cash and Counseling because it might reduce their revenue and place them at a competitive disadvantage relative to privately hired workers. Traditional providers might also object on the grounds that potential workers would not be adequately trained or supervised. Finally, organized labor unions might not support Cash and Counseling because no collective bargaining entities exist to represent privately hired workers (Cameron and Lagoyda 1997).

C. Cash and Counseling Demonstration

The central question RWJF and ASPE posed for the demonstration was: How did Cash and Counseling compare to traditional case-managed PAS? This question was later expanded to consider Cash and Counseling compared to home- and community-based services, including personal assistance. States interested in participating in the demonstration were free to propose Medicaid programs funded under the optional plan benefit, Medicaid programs funded under home- and community-based waivers, or programs funded by state general revenues. These were the demonstration "feeder" programs. Existing consumer-directed programs were excluded.

RWJF and ASPE also stipulated an evaluation employing a rigorous randomized design. Thus, individuals participating in the demonstration were to be assigned either to

a treatment group (to receive the cash benefit) or to a control group (to continue under traditional PAS or home- and community-based services). The effect of the requirement for a randomized design was to limit the demonstration to states with relatively large PAS or home- and community-based care programs or combinations of programs. Only in such states was it possible to obtain the sample sizes needed for the evaluation.

States were expected to include elderly people with disabilities, as well as younger adults with disabilities, in the Cash and Counseling Demonstration. Younger adults with disabilities have long advocated consumer-directed care. The issues in adopting a disability model for personal assistance for elderly people were being debated, and there was policy interest in extending such care to elderly people with disabilities (see, for example, Simon-Rusinowitz and Holland 1993; and Doty, Kasper, and Litvak 1996). The states could also choose to include children with disabilities in the Cash and Counseling Demonstration.

The solicitation anticipated that states would seek a waiver of the federal restrictions on cash payments under the Medicaid program. To grant such a waiver (as in demonstration waivers generally), HCFA imposed terms and conditions, including limitations on the potential impact of the demonstration on public costs. One term and condition required that the cash program impact the federal budget no more than the traditional program being “cashed out.” That is, the cash program was required to be “budget neutral.” HCFA’s traditional approach to calculating budget neutrality involves comparing the monthly cost per recipient of the demonstration program and the traditional program. Another of the terms and conditions for the demonstration waiver limited the potential impact of the demonstration on public costs by limiting the number of new entrants to the PAS program. During the demonstration, the ratio of the number of new entrants to the number of current recipients was not to exceed the historical average.

The demonstration solicitation required that the cash benefit cover a broad range of services (such as equipment and home modifications) in addition to personal assistance workers. Furthermore, the solicitation anticipated that spouses and parents of minor children might be hired as personal assistance workers and that states would have to seek a waiver of the federal restriction on such hiring.

Consistent with the Cash and Counseling model, the demonstration solicitation required the provision of counseling services. These services were to help clients by giving them information and advice, teaching them, and providing support services, including assisting with payroll and bookkeeping activities. Demonstration states were free to decide exactly what counseling services to offer.

Seventeen states submitted bids in response to the solicitation for the Cash and Counseling Demonstration. Four states were selected: Arkansas, Florida, New Jersey,

and New York. New York dropped out of the demonstration before beginning operations; its local social service districts had relatively little interest in participating.

This report on Arkansas is one of a series of three. Each report tells the story of the implementation of the Cash and Counseling model in a particular state.

D. Design of the Evaluation

Mathematica Policy Research, Inc. (MPR) is evaluating the Cash and Counseling Demonstration. The evaluation consists of two inquiries. These inquiries: (1) estimate the impacts of provision of a cash benefit in lieu of personal assistance or home- and community-based services, and (2) document and analyze the implementation of the Cash and Counseling model as it unfolded. These two areas of inquiry are interrelated, as impacts can be interpreted and generalized only in light of how the Cash and Counseling model was implemented.

1. Evaluation of Impacts

MPR will consider impacts on consumers, caregivers, and public costs.

a. Planned Analyses

Cash and Counseling is expected to affect consumers' use of, unmet need for, and satisfaction with PAS. As a result, it may also affect their health and functioning. Because consumers purchase PAS on their own, rather than relying solely on agencies, they are likely to have more control over who provides their PAS, and how and when these services are delivered. Consumers may use different amounts or mixes of services than they would have received under traditional Medicaid PAS. They may also use their funds to buy equipment or devices to increase their independence. The greater flexibility that the cash benefit provides should reduce unmet need and improve satisfaction with PAS. If the quality of consumers' PAS improves, it may also improve independence and disability-related health. Although the expected effects of the program are to improve consumer outcomes, MPR will also assess whether any outcomes worsen.

Cash and Counseling could affect caregivers in several ways. Family and friends providing unpaid care to consumers prior to enrollment in the demonstration could face fewer demands on their time if consumers hire attendants or use the cash benefit to purchase assistive devices. If consumers mismanage the benefit, however, unpaid caregivers may need to provide more care than they did before. Likewise, unpaid caregivers' emotional stress may decrease or increase. MPR will also investigate the experience of caregivers who are hired and paid under the demonstration. The working conditions, job satisfaction, and physical and emotional strain that paid caregivers

experience will be measured and compared to that of agency workers providing care to control group members.

MPR will estimate Cash and Counseling's effects on Medicaid costs for PAS alone and for all costs paid by Medicaid and Medicare. Costs for personal assistance may increase or decrease, depending on the monthly payment rates. Costs for other health care may also increase or decrease. If consumers receiving the cash benefit are more likely to receive care when they need it, they may have fewer falls or pressure sores (for example), and thus have lower costs. On the other hand, if recipients of the cash benefit hire workers who are less well trained than agency workers, consumers' health may suffer, resulting in higher costs.

Separate analyses of subgroups of consumers will be conducted if sample sizes for these subgroups are sufficient to yield adequate precision. Key subgroups of interest include groups of consumers defined by age and by the length of time the consumer has received PAS.

b. Major Data Sources for the Impact Evaluation

The main sources of evaluation data for the impact analyses are (1) telephone surveys with demonstration participants and their caregivers, and (2) Medicare and Medicaid enrollment and claims data. Individuals who agree to participate in the demonstration must complete a baseline telephone interview before they can be randomly assigned to the treatment or control group. Four months after enrollment, MPR interviews treatment group members to learn about their early experiences with the program. Nine months after enrollment, MPR interviews treatment and control group members to collect information on satisfaction, quality of care, quality of life, use of other formal and informal care, and health and functional status. Around the same time, unpaid caregivers identified at baseline are interviewed about the type and amount of care the unpaid worker provides, their relationship with the consumer, and their satisfaction with the paid care the consumer receives. Samples of paid workers identified in the nine-month survey are also interviewed about earnings and benefits, job satisfaction, and problems encountered on the job. Medicaid and Medicare claims and enrollment data will be used to study the cost of PAS, the use and cost of medical services, and the participation rate in personal assistance programs.

2. Process Analysis

The evaluation includes a second component, which examines program structure and implementation. This process analysis, of which this report is a part, has two objectives. First, it documents demonstration operations and the context in which the demonstration operated for each of the three states (Arkansas, Florida, and New Jersey) participating in the Cash and Counseling Demonstration. Second, it develops lessons about designing

and managing a Cash and Counseling program. Specifically, the process analysis seeks to address three major sets of questions:

1. How did Arkansas structure its Cash and Counseling program, and what led it to adopt this structure?
2. How did Arkansas implement its program? Did it implement it according to its plans? If not, how and why did it depart from its plans?
3. What lessons can we learn from the Arkansas experience about structuring and operating a Cash and Counseling program?

The process analysis is based primarily on three data sources. The primary source is in-person interviews conducted with:

- State officials of the Division of Aging and Adult Services (DAAS) who were responsible for the cash program
- Staff of IndependentChoices, including the program administrator, another member of the program staff in the central office, one of the outreach/enrollment nurses, and the certified public accountant who acted as a consultant to the state for fiscal activities
- Staff of both of the counseling/fiscal agencies, including the directors of the agencies, administrators of the cash program at the agency, the counseling supervisors, two full-time counselors in each agency, and the bookkeepers at each agency (some of whom combined more than one role)
- Staff of traditional providers, including the directors of two Area Agencies on Aging (AAAs) and of the Arkansas Department of Health
- Two advocates for younger adults with disabilities (the AAA directors were interviewed as advocates for the elderly as well as traditional providers)

With the help of state program staff, we identified traditional providers and advocates who had long been involved with IndependentChoices and were knowledgeable about its design and implementation. One had been a vocal critic of the program. It was not possible to interview all of the counselors at the larger counseling/fiscal agency; we asked the program administrators to at the larger agency to identify counselors who would be able to generalize from their experiences and would be available to speak to us during our visit.

These interviews were semi-structured and relied on interview guides. The topics concerned the design, structure, and implementation of IndependentChoices and the attitudes of stakeholders toward the program. The interviews were conducted in spring 2000 in Little Rock and other parts of Arkansas.

The second source of information for the process analysis is demonstration documents, such as demonstration state protocols prepared for CMS, state quarterly reports to RWJF, and forms and materials for consumers and consultants. These documents were collected throughout the course of the demonstration and maintained in evaluation files.

The third data source is information obtained by the authors through participating in project meetings and telephone conference calls which included reports of project status and discussion of issues facing the Cash and Counseling states. The authors attended project meetings, which were held twice a year. One of the authors regularly participated in telephone conference calls with state project staff which were held weekly (later biweekly) throughout the demonstration. The status of the Cash and Counseling Demonstration in each state was reviewed at the meetings and on the telephone conference calls.

The primary limitation of the process analysis is that it relies to a large extent on the reports of those who were interviewed in person and the reports of state staff during telephone conference calls. The interviewees were extremely knowledgeable and their reports are certainly credible. Moreover, we have collected information on key topics from multiple perspectives in order to minimize the possibility of error based on misconception. Nevertheless, the report is based primarily on perception. When the quantitative analyses are complete, we will have additional evidence about some--but not all--of the issues considered in this report.

E. Guide to this Report

This report on the implementation of the Cash and Counseling model in Arkansas is presented in 11 chapters. Following this introductory chapter, Chapter II presents a description of the goals of the state and other key stakeholders and the approach that Arkansas adopted to critical issues in the design of its cash benefit program, IndependentChoices. Chapter III describes the process of selecting organizations to provide counseling and fiscal services and the organizations that Arkansas chose. Chapter IV is a description of outreach to develop community interest in the cash program. Chapter V describes the enrollment process for IndependentChoices. Chapter VI discusses the development and approval of cash management plans and the uses of cash. In Chapter VII, we describe the selection and functioning of representatives for consumers unable to manage the cash benefit themselves. Chapter VIII considers how consumers fulfilled their role as employers, with the assistance of counselors and bookkeepers.

Chapter IX discusses monitoring and the lack of abuse of the cash benefit and exploitation of the consumer. Chapter X considers whether the demonstration was implemented as planned, summarizes lessons about the components of the project discussed in Chapters IV through IX, and describes the lessons of the Arkansas experience that cut across components of the program. Finally, Chapter XI looks at Arkansas' plans for the future and for an ongoing Cash and Counseling program.

II. DESIGNING INDEPENDENT CHOICES: ISSUES AND DECISIONS

The solicitation for demonstration proposals provided the basic outline for the Cash and Counseling demonstration programs. It stipulated that the cash benefit was to be provided in lieu of traditional Medicaid personal assistance services (PAS) services and was to cover a variety of goods and services to promote independence. Furthermore, counseling was to be provided to help consumers manage the cash benefit and perform the duties of an employer.

Many design decisions were required to flesh out the program that Arkansas proposed in response to the solicitation. Most of these decisions were made prior to the submission of Arkansas' proposal in February 1996 or during the design phase for the demonstration--that is, between October 1996 (when Arkansas received funding from the Robert Wood Johnson Foundation [RWJF]) through the end of November 1998. The following month (December 1998), demonstration operations began in full. For the reader's convenience, Table II.1 lists a few key dates for the design phase and the first months of operation.

TABLE II.1. Key Dates of Design and Early Operations of the Cash and Counseling Demonstration in Arkansas	
Date	Event
February 1996	Arkansas submitted proposal to RWJF
October 1996	Arkansas received funding to begin to design its program
May 1998	Arkansas began community information campaign
October 1998	Centers for Medicare and Medicaid Services (CMS) readiness review completed
November 1998	Direct marketing campaign begun
December 1998	Arkansas began to enroll Medicare beneficiaries
January 1999	First cash benefit paid to a beneficiary

In this chapter, we first describe the state's goals for its Cash and Counseling program and the reaction of other important actors in the state to the prospect that a cash benefit would be available in lieu of Medicaid PAS. The rest of the chapter describes the major issues that arose in designing the Cash and Counseling Demonstration and Arkansas' approach to addressing these issues.

A. Goals and Perceptions

When Arkansas applied for a grant for the Cash and Counseling Demonstration in February 1996, it had two major personal assistance programs; both were part of its Medicaid program. These operated under (1) the state Medicaid plan, as an optional benefit under federal regulations; and (2) a home- and community-based waiver program for the elderly. The waiver program is called ElderChoices and is designed to “wrap around” the state plan PAS (that is, supplement these services) for those elderly community residents who require an institutional level of care. In addition, when the demonstration proposal was submitted, the Arkansas Spinal Cord Commission operated a small personal assistance program with state funding--Arkansas' only consumer-directed program at the time.

The host state agency in the Arkansas Cash and Counseling Demonstration was the Division of Aging and Adult Services (DAAS) within the state's Department of Human Services (DHS). DAAS also had primary responsibility for managing the ElderChoices waiver program. Other DHS divisions involved in the Cash and Counseling Demonstration included the Division of Medical Services (DMS), which had management responsibility for the state plan Medicaid program.

Despite major changes in state administration, the state executive branch remained committed to consumer direction from the time of preparation of the grant proposal throughout the course of implementation of Independent Choices. The grant proposal was submitted under a Democratic governor, who was succeeded by a Republican governor before the grant was awarded. During the four years following the submission of the proposal, four different individuals served as director of the DHS, but during this entire period, there was no change within the leadership at the DAAS.

1. Goals for the Cash and Counseling Program in Arkansas

During the months prior to Arkansas' decision to apply for a grant under the Cash and Counseling Demonstration, advocates for adults with disabilities in Arkansas had been pressing for the adoption of personal assistance programs that would give these adults more control over their services. In one incident, a leading advocate had chained himself to the governor's desk to draw attention to the needs of people with disabilities. The Cash and Counseling Demonstration offered Arkansas and the DHS an opportunity to seize the initiative by implementing a progressive program.

Arkansas had three immediate goals for its Cash and Counseling program. The first was to assess the extent of demand for such a consumer-directed program. The second was to test whether it could operate efficiently within the environment of the state of Arkansas. In other words, Arkansas wanted to test to what extent a cash program could fit “into the way the state does business.”

The third goal was to assess whether a cash program could serve people with disabilities who were not being served by the traditional system of PAS. For the past few years, home care agencies in Arkansas had been unable to serve a minority of those who apply for PAS. Many of the people who went without services were residents of rural areas.

Several factors seem to explain the inability of home care agencies to serve all their clients. First, the unemployment rate was low, making it difficult for home care agencies to find workers, especially in rural areas where the supply of potential workers usually was small. Second, the time required to travel to rural areas made it prohibitively expensive for agencies to send workers from more urban areas to the homes of clients living in rural areas. Travel time to rural areas also limited the willingness of home care agencies to hire family members to care for clients. An agency's policy might be to send a nurse into the home periodically to supervise the worker, and the time required for nurses to travel to rural areas made such supervision expensive.³ Finally, some clients were dissatisfied with agency aides. A few "ran through" all the aides an agency had on staff. Some Medicaid beneficiaries did not want strangers to come into their homes to care for them.

Arkansas did *not* hope that its Cash and Counseling Demonstration would produce savings of state funds. The federal government grants demonstration waivers of the Medicaid regulations only to programs that are intended to be budget neutral, and the state of Arkansas shared the goal of constraining the cost of the cash program so that it was no larger than that of the traditional program. Cost *saving*, however, was not a state goal from the time the proposal was submitted. Prior to that time, the DMS within the DHS, had been interested in the potential of the cash benefit program to generate savings. However, the DAAS—which was to house the cash program—was less interested in generating savings. Senior program staff report that the DAAS position prevailed.

2. Reaction of Stakeholders

As the state host agency, Arkansas' DHS—especially the DAAS—was a major stakeholder in the Cash and Counseling Demonstration. As Arkansas was planning its program, the other major stakeholders in the state were the traditional providers of PAS and advocate organizations for elderly and younger adults with disabilities. During the planning of the demonstration, these counseling/fiscal services were chosen only after demonstration planning was nearly complete; thus, these organizations were not major stakeholders in the beginning.)

In the previous section, we described the goals of the DHS for the Cash and Counseling Demonstration. In this section, we describe the reactions of the other stakeholders to Arkansas' plans for a demonstration program.

³ The state did not require nurse supervision for Medicaid PAS.

a. *Providers of Traditional PAS*

The major providers of PAS in Arkansas were nonprofit or public entities, rather than for-profit entities. Roughly three-fourths of Medicaid PAS services in the state were provided by eight Area Agencies on Aging (AAAs), each serving a region of the state, and by the Arkansas Department of Health. The AAAs and the health department also provided other services, such as case management, home health services, and homemaker services--including services under the ElderChoices waiver. While other organizations also provided traditional PAS and waiver services, they did not have the political "clout" of the AAAs and the Department of Health. In addition, the AAAs were advocates for the elderly and closely tied to the state's unit of the AARP (formerly the American Association of Retired Persons).

While some AAAs were more critical of a cash benefit program than others, most of these agencies were resistant to the program early on. Shortly after the AAAs became aware that the proposal had been submitted, their representatives met with the governor and with senior officials of the state DHS and requested that the grant be declined. They also met with members of the Arkansas legislature and voiced their concerns (discussed in the next paragraph). While many members of the state legislature were supportive of the cash program, the AAAs might have succeeded in forcing the state to decline the demonstration grant were it not for the fact that the director of one AAA--himself a vocal critic of the cash program--was publicly discredited during this period. This event frustrated the AAA effort to persuade the state to decline the grant.

The AAAs were generally resistant to a Cash and Counseling Demonstration for several reasons. Because of their professional norms and in their role as advocates for the elderly, the AAAs were genuinely concerned about the health and safety of consumers receiving the cash benefit. They were concerned about the lack of professional training and supervision for workers under the cash program and about the possibility that family members or friends would exploit the consumer by accepting employment but not delivering care as agreed, leaving the consumer without needed care. Agencies were also concerned that consumers would abuse the cash benefit by spending it on goods and services unrelated to their need for personal care. In addition, some agency staff felt that it was unfair to exempt workers under the cash program from the regulations applicable to home care agencies. For example, agency workers were not permitted to assist clients by escorting or transporting them. Agencies were also concerned that consumers might hire away agency workers and about the possible loss of revenue if their PAS clients chose the cash program. As one agency director put it, "Well, good Lord, what if this caught on?" To put this last concern in perspective, one needs to understand that the original goal for the demonstration was to enroll roughly a fifth of all PAS clients served annually in the state.

As planning for the Arkansas cash program neared completion, not all AAAs continued to oppose it. Two AAAs mounted a joint bid to provide counseling/fiscal

services in one region of the state, with one of them as subcontractor to the other. This bid was successful, although the AAAs provided counseling/fiscal services only for a short time (for reasons explained in Chapter III).

As noted earlier, the Arkansas Department of Health is also a major provider of traditional PAS in the state. While the director of the Department of Health was generally supportive of the cash benefit, some staff members at lower levels of the organization were resistant, for reasons similar to those of the AAAs.

Arkansas attempted to ameliorate the remaining concerns of the traditional providers. The Cash and Counseling National Program Office hired a prominent Arkansan who had long been involved with home care policy to assist in educating traditional providers and to build support among them. He spoke with executives of a number of the traditional providers.

By the time of our visit to Arkansas in the spring of 2000, the executives of most traditional providers had muted their criticism of the cash program. However, as described in Chapter IV, it appears that home care aides sometimes criticized IndependentChoices in an effort to persuade their clients not to leave traditional services to join the cash program.

b. Advocates

In the beginning, the advocate organizations for adults with disabilities (as opposed to advocates for the elderly) were strong and vocal supporters of Cash and Counseling. Their support waned somewhat over time, however, although they never became critics of the cash program. The erosion of support from these advocates was partly due to the state's decision not to allow payment to spouses as workers in the demonstration program--a decision that incensed one key advocate. The DAAS made this decision in light of the conservative political climate in Arkansas and determined opposition from providers of traditional PAS. At the time, all of the demonstration states, including Arkansas, were also facing lengthy delays in securing approval by the federal Office of Management and Budget (OMB) of the waivers of the Medicaid regulations. OMB's reluctance to grant the waivers was caused, in part, by the request for payment to legally liable relatives, including spouses and parents of minor children, in the demonstration program. (Prohibition of payment to legally liable relatives was later waived, but Arkansas did not reverse its earlier decision not to allow payment to legally liable relatives.)

Erosion of support for a cash program from advocates for adults with disabilities may also have been due, in part, to change in personnel. Early in the demonstration, a key leader of the Independent Living Movement who had actively supported a cash benefit left Arkansas to assume a position in a neighboring state. While the new leadership of the

Independent Living Movement was generally supportive of the cash program, it was much less active on its behalf.

Finally, during the design phase for IndependentChoices, the Arkansas legislature authorized a new program to permit family members and friends of adults with disabilities to become Medicaid-certified providers of PAS and thus receive payment for caregiving. (The DAAS also manages this program, known as Alternatives.) Work to secure and implement the new Alternatives program may have blunted interest in IndependentChoices among advocates for adults with disabilities.

B. Design Issues and Decisions

The funders and federal regulations--including the terms and conditions of the demonstration waivers--set parameters for the Cash and Counseling Demonstration. Within these parameters, Arkansas made many decisions about all of the major components of the Cash and Counseling model: eligibility and appropriateness, outreach and enrollment, services to be covered by the cash benefit, amount of the benefit, and counseling and fiscal services.

1. Eligibility and Appropriateness

The solicitation for the Cash and Counseling Demonstration permitted states to cash out Medicaid state plan PAS or Medicaid home- and community-based waiver services.

Arkansas had both state plan PAS and waiver services under the ElderChoices program but chose to cash out only the former. It considered also cashing out ElderChoices but decided against that option because doing so would likely strengthen the opposition of the providers of traditional services. Both the AAAs and the Department of Health provided services under the ElderChoices as well as PAS.

After Arkansas had decided to cash out its state plan PAS, it needed to decide which beneficiaries of that program were inappropriate for Cash and Counseling and how to identify them so that they could be screened out. Determining who would be inappropriate for the program proved problematic, for two reasons. First, what characteristics could be used to identify inappropriate cases prior to enrollment? Arkansas initially planned to exclude cases in which consumers were expected to live only a short time, as several weeks were typically required to implement a cash plan. To prevent abuse of the cash benefit, Arkansas also planned to exclude consumers who had a history of substance abuse. However, it seemed unlikely that these two characteristics (terminal illness and history of substance abuse) were sufficient to identify many cases for which the Cash and Counseling program was inappropriate. For example, what characteristics might identify situations with a great potential for exploitation of the consumer? In deciding how to

identify inappropriate cases, moreover, Arkansas also had to consider whether the consumer had a representative available to manage the cash benefit. Would the state require representatives in certain cases, and, if so, how were these cases to be identified? What criteria, if any, would be used to determine if a proposed representative was suitable to manage the cash benefit? Would an individual be permitted to serve both as a representative and a worker under the cash program? Would the state limit the use of representatives if the consumer appeared able to manage the cash benefit without assistance?

The second problem that arose was the legality of excluding those the state believed to be inappropriate. A structured process denying participation might not be legally defensible and thus open the state to liability if a consumer chose to contest exclusion from the program. For example, denying participation to someone because he or she had once been an alcoholic might not be defensible, regardless of the state's desire to prevent abuse of the cash benefit.

After considerable effort--much of it in concert with the other Cash and Counseling states, Arkansas abandoned the attempt to develop a formal process to exclude inappropriate cases. Instead of formal criteria and a formal, structured screening instrument, the states developed a process of self-screening for consumers and representatives. Arkansas developed two forms for this process. The first guided consumers as they thought about the responsibilities they would be taking on and encouraged them to assess their ability to carry out these responsibilities. The second form laid out the duties of a representative and was to be signed by those taking on this role. (Appendix A presents these forms.) Working in conjunction with the other Cash and Counseling states, Arkansas decided not to adopt a formal process for determining when a representative was required; nor did it adopt formal criteria to determine whether a given person was appropriate as a representative. Arkansas did specify that the same individual might not serve as both a worker and a representative. Serving as both a worker and a representative created a possible conflict of interest, since the representative's responsibilities would typically include signing worker time sheets and supervising worker activities. (Chapters V and VII discuss Arkansas' experience with this self-screening process.)

2. Outreach and Enrollment

Outreach to the community was necessary to promote awareness of the Cash and Counseling Demonstration and to increase interest in participation. To be most effective, outreach had to focus on those eligible to enroll so that outreach and enrollment could be coordinated.

The state had to make two interrelated design decisions with respect to enrollment: (1) when these processes were to take place, and (2) who would be responsible for them.

(These decisions, in turn, drove the optimal design for outreach.) The basic options for *timing* of enrollment were to allow consumers to enroll at any time or to require them to enroll at their periodic assessments for PAS. The basic options for *responsibility* for enrollment were for the state (or its designee) to contact beneficiaries directly or to rely on organizations already serving the target population. In the latter case, outreach might also be assigned to these same organizations. These options are considered in more detail next.

Enrollment at assessment (that is, as ongoing recipients of PAS are reassessed to determine the need for continuing care and as new applicants are assessed) had two important advantages. First, the care planning immediately following assessment was the source of the information needed to determine the amount of the cash benefit. Second, enrollment at assessment would generally spread enrollment over time and thus made the process more manageable for state staff. On the other hand, restricting enrollment to the time of assessment was problematic if outreach was to be conducted through direct contact with beneficiaries. If beneficiaries were required to wait for several months before being allowed to enroll, they were likely to lose interest in the cash program altogether.

Responsibility for outreach might be vested in providers of traditional services, other types of organizations, independent assessors under state contract, or state employees. Providers of traditional services might readily couple enrollment with assessment, as the latter is often their responsibility. For example, those conducting assessments might explain the cash program and leave reading materials on the program with the consumer. Consequently, relying on traditional providers to conduct outreach might be more efficient than independent contracting or hiring state employees--other things being equal.

However, objectivity, as well as efficiency, was an important consideration in selecting an approach to enrollment in the cash program. Staff members at traditional agencies in Arkansas who were resistant to the cash program might influence consumers not to participate. In addition, some independent assessors might perceive the cash program as threatening their professional norms (as was true for some in the traditional agencies). On the other hand, in an effort to reach enrollment targets, state employees might "oversell" the cash program to consumers who had limited interest in receiving a cash benefit.

Because of the opposition of the providers of traditional PAS services, Arkansas decided not to give responsibility for outreach or enrollment to these providers, and it divorced outreach and enrollment from the assessment process for which these providers were responsible. To identify interested consumers, Arkansas relied instead on direct mailings to consumers and on publicity, both of which invited consumers to telephone program staff for more information if they were interested in participating. Since interested consumers were required to take the initiative by making contact with the program, the state called its approach to outreach and enrollment, the "bubble up" approach.

Consumers were allowed to enroll at any time, without regard to the assessment cycle. Staff members of traditional programs were not even asked to distribute material on the cash program. Arkansas also hired nurses as state employees to conduct community outreach and to enroll participants in the demonstration, thereby keeping close control of that function. Chapters IV and V describe the implementation of outreach and enrollment in Arkansas.

3. Planning the Uses of the Cash Benefit

The solicitation for the Cash and Counseling Demonstration insisted that states permit the cash benefit to cover a broad range of goods and services--provided that the goods or services helped consumers to function more independently. The solicitation did not envision a Cash and Counseling program that provided unfettered cash, as in an income supplement program. Rather, it anticipated that consumers would be allowed to purchase only certain types of goods and services.

One key issue that arose with respect to the cash benefit was the method by which purchases would be authorized. With little debate, all of the Cash and Counseling states decided to require consumers to develop cash management plans indicating how the benefit was to be spent. There was considerable debate, however, on the procedures for review of cash management plans. A state might require its staff to review all cash plans or delegate authorization to do so to counselors (or their supervisors). Arkansas drew up a list of goods and services clearly covered by the cash benefit. The state permitted counselors to authorize the purchase of any goods or services listed, with review by state staff of any unlisted goods or services. The state wanted to limit its responsibility for review of care plans in the demonstration because it judged that state review would not be workable in an ongoing cash program were Arkansas to adopt one following the demonstration.

During the development of a cash management plan, the availability of goods and services from other public sources needed to be taken into account. It was not in the consumer's interest to use the cash to purchase services that were already available at no cost. Not only did the client incur an unnecessary expense if he or she purchased such goods or services, but the other program might be better able to assist the client. For example, a program focusing on equipment could offer advice on what type of equipment was best under different circumstances. To address this issue, Arkansas had counselors advise consumers about the goods and services available under other public programs during the development (and later revisions) of the cash management plan.

Another key issue was who would be eligible to be hired as a worker. As discussed earlier, Arkansas chose not to permit the hiring of spouses with the cash benefit, although that was allowed under the federal waivers for the demonstration.

4. Amount of Benefit

In a cash program, the amount of benefit may depend on the consumer's level of need or on the level of an existing benefit. Using the existing benefit level is not an option for those new to the traditional program.

Arkansas based the amount of the cash payment on the level of need--defined as the number of hours of care authorized in the existing care plans of current clients of the Medicaid personal assistance program and on newly developed care plans for applicants. These care plans were designed to supplement any care being provided by family members or friends. Nurses employed by traditional providers were responsible for developing care plans for their clients. Instead of having traditional providers develop care plans for new applicants who were interested in the cash program, Arkansas had the outreach/enrollment nurses employed by the state do so. This approach limited the opportunity for traditional providers to dissuade consumers from participating in the cash program.

The timely availability of the information needed to set the cash benefit level was also an issue. Prospective participants cannot be expected to make a commitment to participate in a demonstration of a cash program without knowing the amount of cash they would receive under the program. Arkansas' solution was to request that the traditional agency fax a copy of the current care plan to the outreach/enrollment nurse before the initial enrollment visit. The nurse then calculated the cash benefit level from the hours in that care plan.

A major issue that arises in any program using care plans to set cash benefit levels concerns differences between the amount of service planned and the amount actually received. The amount of service received is generally less than the amount planned. (The care plan typically represents the maximum amount of care authorized; thus, the amount of care received does not exceed the amount planned.) Because the cost of the care received is generally less than the cost of the care planned, a discount rate must be applied to ensure that the costs of the cash program do not exceed the costs of the traditional program if the level of the cash benefit is to be based on care plans.

Care received is generally less than care planned for a variety of reasons. A client may be unexpectedly hospitalized and thus not available when an aide arrives. A home care aide may not appear for work when expected, or an agency may be unable to find enough workers to provide the care it had planned. Agencies sometimes plan for somewhat more care than they expect to render so that they can increase the amount of care without revising the care plan if the client's needs increase. That is, the total hours planned included a "hedge" against possible future increases in need.

Determining the discount rate needed to achieve budget neutrality can be difficult. The ratio of the cost of care received to care planned may differ for agencies and individual clients. As a result, using a single discount rate for all agencies and all clients may unfairly penalize some cash program participants. In addition, those interested in participating in the cash program may receive a different proportion of the care planned for them than participants in the traditional program as a whole. Yet, as a practical matter, those interested in participating in a cash program cannot be identified in advance so that a group-specific discount rate can be prepared.

Moreover, the discount rate needed to achieve budget neutrality may change over time as a result of changes in the ratio of the cost of care received to care planned for participants in the traditional program. That is, the appropriate discount rate may be a "moving target." The ratio of the cost of care received to care planned could change as a result of changes in home care policy or of changes in the home care industry. For example, a particular subgroup of clients might leave the traditional program for a new personal assistance program (such as Arkansas' Alternatives). In such a situation, the ratio of the cost of care received to care planned for the remaining clients of the traditional program could differ from the ratio prevailing before the new program was instituted. With changes in the business cycle, the unemployment rate might fall, causing the supply of aides to become more limited or the reliability of the aide workforce to fall and result in more "no-shows." Either type of labor market change could affect the ratio of the cost of care received to care planned, at least until agencies adjusted their care planning to conform to the changes in the labor supply.

Arkansas devoted considerable effort to developing a discount rate. Because it believed that some agencies had historically set care plan hours higher than other agencies, the state developed agency-specific rates. State staff collected care plans for samples of clients from agencies throughout the state. For the sample individuals, they compared the cost of care received during the period covered by the care plans to the cost of care planned. Because some smaller agencies did not respond to the state's request for care plan data, all smaller agencies were grouped and assigned a single discount rate. The discount rates ranged from 70 to 91 percent.

For those new to the Medicaid personal assistance program, Arkansas applied a minimal discount rate (91 percent) to the hours in the care plans developed by its nursing staff to determine the cash benefit level. It selected the rate at the upper end of the range that it observed among traditional agencies because its enrollment nurses were trained to plan for current care needs only, whereas (as discussed earlier) some traditional agencies apparently had been building in a hedge against possible future increases in need.

The discounted care plan hours were cashed out at \$8.00 per hour. The difference between \$8.00 and the hourly rate the state paid to traditional providers (\$12.36) was used to cover the cost of counseling/fiscal services.

5. Counseling and Fiscal Services

Arkansas faced several major issues concerning counseling and fiscal services. The state had to decide what counseling and fiscal services would be offered, how these services would be organized, and how they would be paid for.

a. What Services to Offer

Many features of counseling/fiscal services are intended to help consumers and may be used at their discretion. Others are intended to prevent abuse of the cash benefit and exploitation of the consumer and are mandatory. Arkansas had to decide which features of counseling/fiscal services would be offered and which would be mandatory. In particular, counselor assistance with development of the cash management plan might be discretionary, while counselor review and approval of the uses of cash might be mandatory. Counselor assistance with recruiting, hiring, training, and supervising workers might be discretionary, but the state might require that the fiscal entity prepare the appropriate tax and unemployment insurance forms (or ensure that the consumer did so). Periodic counselor contact with consumers might be mandatory to prevent abuse and exploitation, but the nature and frequency of such mandatory contact had to be determined. Furthermore, if a consumer declined to use fiscal services, the state might require that he or she pass a test on preparation of payroll documents to ensure that federal and state tax liabilities were met.

In addition to these basic services, a counseling/fiscal agency might perform a number of other services for consumers. These include maintaining a worker registry to help consumers identify workers to hire, assisting in securing background checks for potential employees, maintaining staff to serve as back-up workers if a consumer's regular workers are unable to care for him or her, and maintaining a peer support group. Counselors might also be responsible for enrollment and for reassessment of changes in the care needs of participants in the cash program.

The Arkansas design for IndependentChoices made three aspects of counseling/fiscal services mandatory. First, counselor review was required for the proposed initial cash plan and all subsequent proposed changes in the uses of cash that were inconsistent with the cash plan. Second, counselors were required to visit consumers quarterly and call them monthly to monitor their circumstances and use of the cash benefit. Third, consumers who chose not to use the fiscal services for preparation of payroll taxes and other documents were required to demonstrate knowledge of the preparation of these documents.

With respect to additional services, Arkansas required that counselors conduct reassessments for participants in the cash program but did not require counseling/fiscal agencies to provide background checks, a worker registry, back-up workers, or a peer

support group. As indicated earlier, Arkansas hired state employees to conduct outreach and enrollment.

b. Organization of Counseling and Fiscal Services

Arkansas faced a number of options in deciding how to organize assistance for consumers receiving the cash benefit. First, it could separate counseling and fiscal functions, assigning them to different organizations, or combine counseling and fiscal functions in a single host organization (the Spectrum model). The major argument for separating the counseling and fiscal functions is the difference in the expertise required. The major argument for combining counseling and fiscal functions is that they are so closely linked that combining them enhances efficiency.

Second, Arkansas could choose to have one host organization serve the entire state (for counseling, fiscal services, or both) or to have regional host organizations. Having one host organization may take better advantage of economies of scale. If the consumer is to have an opportunity to choose among providers of assistance, however, multiple host organizations must be available. Moreover, a single host organization might not be able to cover all parts of a state. If Arkansas decided to have separate entities providing fiscal and counseling assistance, it might choose different numbers of host organizations for the two types of functions--such as a single statewide fiscal entity but multiple counseling entities from which consumers were allowed to choose.

Third, Arkansas could choose to integrate counseling and fiscal services with similar services already provided by existing organizations, or it could develop organizations whose primary or sole function was to provide counseling or fiscal services. The major arguments against integration were that the philosophy of consumer direction might conflict with the philosophy of existing organizations and that responsibilities for existing services might conflict with the assumption of new responsibilities under the cash program. These arguments seem to apply chiefly to counseling services. Thus, if Arkansas chose not to combine counseling and fiscal functions, it might develop separate organizations to offer counseling but integrate cash program fiscal services with existing fiscal services.

Arkansas chose to combine counseling and fiscal services. The state believed that combining these services would be advantageous because many counselor duties relate to uses of the cash. It also believed that the state could monitor the counseling/fiscal agencies more easily if the two functions were combined, since its travel and administrative costs would be reduced. While Arkansas permitted the integration of counseling/fiscal services into organizations already providing similar services, it was also open to the development of separate organizations.

Arkansas split the state into four regions and planned for a single agency providing both counseling and fiscal services in each region. It recognized that this approach limited

consumer freedom of choice but noted that consumers were free to change counselors (within the counseling agency) if necessary. In addition, the state provided a toll-free number for complaints.

Arkansas based the regions for the cash program on the regions electing members to the U.S. Congress, modified to contain roughly equal numbers of PAS recipients. Arkansas deliberately picked regions that were not contiguous with the regions served by the eight AAAs in the state. By doing so, Arkansas ensured that AAAs would have to cooperate with one another to be selected to serve as host organizations for counseling/fiscal services.

c. Paying for Counseling and Fiscal Services

Another issue that Arkansas faced in designing the Cash and Counseling program was how to pay host organizations for the counseling and fiscal services they provided. First, the state had to decide whether the consumer was to be charged for nonmandatory services. For example, were consumers to be charged a monthly fee for bookkeeping and tax preparation if they chose to use fiscal services? The major argument against such consumer charges was that it might discourage consumers from using a service despite its benefit to them.

Second, Arkansas had to decide how to structure its payment for counseling/fiscal services. The basic options were a fee-for-service or capitated approach. One important issue regarding a capitated approach was that the level of counseling services required by a given consumer might decrease over time as he or she (or a representative) mastered the responsibilities of an employer. Under either a capitated or fee-for-service approach, it might be feasible to pay for some specific services under another authority, rather than including them in the blanket payment for counseling/fiscal services. For example, reassessment might be paid for as a separate Medicaid service, rendered by staff of the counseling entity or by someone outside of the cash program.

Arkansas decided in favor of a capitated approach to payment for counseling/fiscal services. The payment (labeled a management fee) fell over the course of two years, from a high of \$115 a month during the first six months following demonstration enrollment to a low of \$75 a month during the last six months of the two-year period.⁴ Because it wanted consumers to avail themselves of the counseling and fiscal services, Arkansas did not institute a consumer charge for bookkeeping and tax preparation services. In the next chapter, we describe the counseling/fiscal agencies that Arkansas selected.

⁴ The terms and conditions for the demonstration specified that the cash benefit was to be available for at least two years to each enrollee.

III. COUNSELING/FISCAL AGENCIES

The selection of the agencies to provide counseling and fiscal services marks the transition from the design of Arkansas' Cash and Counseling Demonstration to its operation under the program name of IndependentChoices. In this chapter, we describe the process Arkansas used to select counseling/fiscal agencies, the agencies themselves, and the procedures the state used to ensure the quality of counseling and fiscal services.

A. The Selection Process

Arkansas issued a formal solicitation to select its counseling/fiscal agencies. The solicitation listed several criteria pertaining to the organization's business and fiscal experience. To help eliminate organizations that might not be viable, acceptable bidders were required to have been in business at least two years. Furthermore, they had to have a minimum of two years of experience in keeping payroll records and maintaining the confidentiality of these records. Acceptable bidders also had to have a certified public accountant available to consult with them about fiscal issues. Finally, bidders were notified that they would be required to provide a substantial financial bond if they were selected as a counseling/fiscal agency.

Arkansas also tried to use the formal solicitation process to ensure that successful bidders were committed to IndependentChoices. The solicitation indicated that the successful bidder would be required to send staff members to training sessions on the cash program *before* beginning to receive payment under the program.

Four proposals were received. The number of bidders may have been limited by the requirement to post a bond and by uncertainty about the number of clients who would choose to participate, leading to uncertainty about the cash flow to the counseling/fiscal agency under the cash program.

Awards were made to three bidders. (The fourth bidder, an Independent Living Center, was eliminated immediately because it proposed a management fee that exceeded the maximum provided for in the solicitation.) One of the three successful bidders was an Area Agency on Aging (AAA). The other two successful bidders were also organizations providing human services.

Despite the criteria in the solicitation emphasizing experience with payroll records, none of the four bidders specialized in payroll processing, and none proposed such companies as subcontractors. An organization providing fiscal services in other states had expressed some interest in submitting a bid as a subcontractor. While representatives of

this group attended the bidder's conference, the group did not join in a proposal. Possibly, the requirement that counseling and fiscal services be combined discouraged bids from organizations with more fiscal expertise but little or no human service expertise, as a joint bid would be required in that situation.

B. The Counseling/fiscal Agencies

One of the successful bidders to become a counseling/fiscal agency was a for-profit agency specializing in the provision of rehabilitation therapy. Staff members included health care professionals trained in speech, occupational, and physical therapy and in nursing. This agency was faced with cutbacks in the Medicare home health program and was looking for other business opportunities. It did not provide traditional Medicaid personal assistance services (PAS).

Another successful bidder was a nonprofit organization providing a variety of supportive services to children and to adults of all ages in an isolated and underserved rural county. Among its programs were infant day care, a school serving able-bodied children and children with physical disabilities, health care screening for children under Medicaid, and a small program providing traditional Medicaid PAS for adults. This organization responded to the IndependentChoices solicitation because it was looking for opportunities to expand services to individuals with disabilities and the elderly in the county it served. The counseling staff at this agency had a human services background, including extensive work in programs to help people with disabilities function independently.

The third successful bidder was the AAA, also a nonprofit agency, and a provider of Medicare home health care and traditional Medicaid PAS. (A second AAA was a subcontractor.) The AAA nursing staff members were to serve as counselors for the cash program in addition to their duties as case managers for the agency's Medicare and Medicaid programs.

The AAA withdrew from the cash program a few months after operations began, citing difficulty in maintaining cash flow. While the AAA had bid the maximum management fee allowed in the solicitation, the caseload in the cash program--and, consequently, the agency's cash flow from IndependentChoices--was small at that time. In addition, the agency had been experiencing financial difficulties as a result of federal reductions in coverage for another of its services, Medicare home health care. Its director did not want more financial risk.

Other factors also may have figured in the decision of the AAA to withdraw from the cash program. The AAAs are peer agencies that generally do not subcontract with one another, and the new relationship proved managerially cumbersome. In addition, the AAA nurse case managers might not have been committed to the cash program. State

program staff perceived the behavior of the nurse case managers as “too prescriptive” and thus not in keeping with the philosophy of consumer direction. The slow buildup of cases once operations started may have contributed to this problem, as a nurse case manager may not have received his or her first cash program case until a number of weeks after completing training for IndependentChoices.

When the AAA withdrew, Arkansas asked one of the other counseling/fiscal agencies to expand its operations to include the region of the state that the AAA had been serving, and the agency agreed to do so. This agency was already serving two other regions in Arkansas, since the state had asked it to serve a region not covered by the three acceptable bids submitted. (Each of these three bids covered only one region of the state.) Expansion may not have been an option for the other counseling/fiscal agency, as the focus of its host organization was service to a particular county.

Consequently, for most of the demonstration, one counseling/fiscal agency served one region of Arkansas (roughly, the northeast quadrant), and another agency served the other three regions (the bulk of the state).

C. Quality Assurance

To ensure the quality of counseling/fiscal services, Arkansas provided training and technical assistance, established performance standards, and monitored agency performance relative to those standards.

1. Training and Technical Assistance

Before operations under the cash program began, Arkansas provided training for counselors, with state program and enrollment staff members serving as trainers. While the training covered the philosophy of consumer direction, its focus was on procedures under IndependentChoices. For example, the curriculum covered the regulations on payroll taxes so that counselors could explain these responsibilities to consumers interested in managing their own cash benefit.

The state also gave the counseling/fiscal agencies considerable technical help in fiscal issues. This was necessary, as none of these agencies was sophisticated with respect to accounting or tax preparation. To assist the agencies with fiscal issues, Arkansas identified a certified public accountant who had extensive experience working with small organizations. He set up a basic chart of accounts and identified accounting software (Peachtree) that supported treating each consumer as a separate “minibusiness,” with his or her own chart of accounts and income statement. Each consumer must be considered separately because separate payroll tax forms must be filed for each (as required by the U.S. Internal Revenue Service [IRS]). Both of the

counseling/fiscal agencies adopted Peachtree as their accounting software, making it easier for the state to monitor their activities.

In addition, the National Program Office for the Cash and Counseling Demonstration assisted all the states and their counseling/fiscal agencies with fiscal issues. First, the National Program Office hired a consultant to work with the IRS on behalf of all of the demonstration states to resolve issues pertaining to the appropriate tax forms to be filed by a fiscal agent on behalf of a consumer. The National Program Office also hired a consultant to develop a consumer manual on federal and state fiscal issues (such as federal payroll taxes and state unemployment compensation regulations). This consumer manual was tailored to the laws and regulations of each state.

During training and the initial weeks of program operations in Arkansas, state program staff honestly discussed issues about which the state staff was uncertain with counseling/fiscal agency staff. Examples of such issues included the speed with which the caseload would build and the effects of the opposition of the traditional agencies. Counseling/fiscal agency staff reported that they appreciated the state's candor.

2. Standards and Monitoring

The IndependentChoices contracts for the counseling/fiscal agencies provided a number of standards to ensure the quality of counseling and fiscal services. Under IndependentChoices, counselor caseloads were limited to a maximum of 75 consumers (the typical caseload for case managers in the United States is about 50). Notice was required if a counseling and fiscal agency would not be able to complete an initial home visit with a consumer (to begin to develop the cash management plan) within seven days of receiving the referral. The contracts with the counseling/fiscal agencies required that the counselor meet with the consumer face-to-face at least once a quarter (this requirement was later relaxed). The contracts also required that the counseling/fiscal agency also maintain a complaint log, which was reviewed during on-site monitoring visits by state staff. This was in addition to a statewide toll-free number for complaints and a state-maintained complaint log. Finally, the contracts provided for an audit of the agency's financial records by a certified public accountant. The chief purpose of the audit was to ensure that funds were not being diverted from consumer accounts.

D. Organization of Counseling/Fiscal Staff

The two counseling/fiscal agencies organized their staff in similar ways, with some minor differences.

The counseling/fiscal agencies added counseling staff members over time, as caseloads increased. At the time of our visit, the smaller counseling/fiscal agency had two

full-time counselors on its staff, and the larger agency had three full-time and three part-time counselors. One of the latter was also the counseling supervisor; the two other part-time counselors worked for the agency primarily on weekends.

In both of the counseling/fiscal agencies, counselors initially had separate caseloads. That is, they were assigned to assist different consumers. However, it soon became clear in both agencies that maintaining separate caseloads was unworkable. Consumers called to speak to a particular counselor, only to find that he or she was out in the field seeing another consumer. In addition, since caseloads were initially assigned as consumers enrolled, the homes of consumers in a given counselor's caseload were generally scattered across a wide area, making it difficult for the counselor to visit several consumers in his or her caseload during a single day. Both of the counseling/fiscal agencies moved to a shared-caseload approach. At one agency, a counselor kept a consumer until a couple of weeks after the cash benefit started. Thereafter, at the counselor's discretion, that person was moved to the shared caseload.

The shared-caseload approach had two major advantages. First, all counselors knew all the consumers and could respond to telephone calls from any of them or visit any of them (if nearby). Consequently, efficiency was increased as telephone tag and travel time were reduced. Second, the shared-caseload approach allowed counselors with particular expertise to respond to issues related to their area of expertise. For example, a counselor who was a nurse was relied upon when more complex health issues arose, and the speech therapist was expert on communication techniques. Case Example III.1 describes how the speech therapist brought these skills to bear. This second advantage of the shared-caseload approach is less likely to apply to very small counseling/fiscal programs, as they are less likely to have counselors with a variety of areas of expertise.

Case Example III.1: Value of Speech Therapy in Counseling

The speech therapist had been trained in communication and cognitive therapy. She could analyze learning styles and employ different teaching approaches as appropriate. She helped other team members by suggesting communication techniques for consumers with hearing problems and mild cognitive impairment.

At the counseling/fiscal agency serving the bulk of the state, weekly staff meetings were held to inform all counselors of the progress of consumers on the caseload. (Since there were only two counselors at the other agency, staff meetings could be more informal.) Initially, the counselors considered the weekly staff meeting time-consuming. Over time, however, these counselors became convinced that the meetings were beneficial. The advantages of these staff meetings were efficiency and the provision of several perspectives on an issue.

The responsibilities of the bookkeepers differed at the two counseling/fiscal agencies. In the larger of the counseling/fiscal agencies, the bookkeeper for the cash program was only responsible for that program. In the other agency, the bookkeeper was also responsible for the bookkeeping for other activities of the host organization.

Next (in Chapters IV through IX), we describe the implementation of each component of IndependentChoices by the state of Arkansas and these two counseling/fiscal agencies.

IV. OUTREACH: COMMUNITY INFORMATION AND MARKETING

Confronted with the opposition of agencies that had traditionally provided Medicaid personal assistance services (PAS), Arkansas had decided to permit consumers to enroll in IndependentChoices at any time (without regard for periodic assessments) and to retain responsibility for the critical task of outreach to generate enrollment.

Generating enrollment was an especially urgent and demanding task because the demonstration was the subject of a rigorous evaluation. A large caseload was needed to yield the evaluation sample necessary to be confident of detecting any program impacts. Moreover, this caseload was to be generated quickly, as only a year of intake was planned for the evaluation sample (the intake period was later extended). Thus, outreach for the Cash and Counseling Demonstration was a much more difficult task than would normally be true for an ongoing program.

In this chapter, we describe the operation of outreach under IndependentChoices. Outreach in Arkansas had two basic components: (1) a locally based campaign to inform the community, especially potential referral sources, about IndependentChoices; and (2) a centralized campaign focusing primarily (but not exclusively) on marketing the program directly to consumers who were eligible to participate.

A. Local Community Information Campaign

In spring 1998, anxious to begin to operate the cash program and under pressure from advocate groups and from senior officials in the state government, the Division of Aging and Adult Services (DAAS) hired four nurses (as state employees) to serve as outreach and enrollment staff for IndependentChoices. In May of that year, the state embarked on a community information campaign. Direct marketing to eligible consumers began in November 1998, and enrollment and initiation of counseling/fiscal operations began in December 1998.⁵

The information campaign was primarily designed to reach those in the community who might refer consumers to IndependentChoices to educate them about the program and to generate interest in “this innovative way” to provide personal assistance services.

⁵ Participants in the demonstration signed consent forms during an enrollment home visit. However, the date of random assignment (rather than the date the consent form was signed) was adopted as the demonstration enrollment date. Thus, those who signed a consent form but withdrew consent prior to random assignment, were not considered enrolled.

Working out of their homes in the four quadrants of the state, outreach/enrollment staff spread the word about IndependentChoices to potential referral sources, compiling a referral resource directory as they did so. They visited the county offices of the state Department of Human Services (DHS) in every county across the state. They visited discharge planners at hospitals and nurses at physicians' offices (seldom visiting the physicians themselves) in towns and cities across Arkansas to acquaint them with the cash program. In rural areas, home demonstration clubs of the Agricultural Extension Service, which educate rural residents about homemaking tasks (for example, canning) proved a good outreach venue. Enrollment staff stopped at mayors' offices to get directions and often ended up giving impromptu presentations on the program to the mayor and his or her staff.

Enrollment staff members also gave speeches. They spoke at senior centers (often as the luncheon speakers at meal programs for senior citizens) and to civic organizations (such as the Rotary Club and the Kiwanis Club). Often, they showed a short video on IndependentChoices that had been developed with National Program Office funding and then tailored to reflect the features of the cash program in each of the states. At these presentations, they also handed out copies of a draft brochure about IndependentChoices.

The community information effort helped to inform the marketing effort that followed. Questions raised about the program during the community information sessions helped the state to hone the IndependentChoices brochure to address the issues that people typically raised and to do so in a way that was easy to understand. The brochure was made available in local communities. It was distributed at community meetings and copies were available to the public in various community locations, including the county offices of the Arkansas Department of Health, physician offices, and drug stores.

The community outreach effort succeeded in generating early interest in IndependentChoices. The draft brochure included a tear-out postcard requesting more information about the program. During summer 1998--before marketing began in earnest--state staff in Little Rock were pleasantly surprised when potential participants returned some of these postcards. Clearly, word about the program was being passed along to those for whom it was intended.

As noted, the community information campaign began about six months before the beginning of enrollment and counseling/fiscal operations. Arkansas could not begin to enroll consumers in the cash program or provide counseling/fiscal services until the waivers necessary for the demonstration were approved. When the last waiver was approved in November 1998, the Centers for Medicare & Medicaid Services (CMS) quickly completed a readiness review, and the enrollment in IndependentChoices began in December 1998. The delay between the initiation of the community information campaign and of enrollment likely reduced the usefulness of the campaign since some potential

referral sources in the community would have forgotten about the cash program as the weeks and months slipped by.

After direct marketing began in November 1998, outreach/enrollment staff had relatively little time to devote to the community information campaign. The initial direct marketing generated considerable interest in the program and resulted in a substantial backlog of consumers seeking to enroll in the program. Consequently, the outreach/enrollment staff had little time for the community information campaign during the initial weeks of enrollment. Thereafter, the campaign did continue, but at a reduced level. Over a year after enrollment began, a fifth person was added to the outreach/enrollment staff, and one of his responsibilities was to assist with the community information campaign.

The ongoing community information campaign included one type of activity that had not been included initially. Early in 2000, the Cash and Counseling National Program Office funded focus group discussions with four groups of professionals who were potential referral sources for IndependentChoices: (1) physicians, (2) nurses, (3) social workers, and (3) pharmacists. Of these four groups, the social workers and pharmacists seemed enthusiastic about the cash program.

While the initial community information campaign had not focused on pharmacists, subsequent experience with the development of cash management plans suggested that they might be good referral sources. A number of participants in IndependentChoices used the cash allowance to purchase medications not covered by the state's Medicaid program, as well as nonprescription medications. (The uses of the cash benefit are discussed in detail in Chapter VI.) The participants in the pharmacist focus group suggested that materials describing the program be printed for distribution at local pharmacies and that the video describing the cash program be made available for pharmacists to loan to interested parties. Focus group members also suggested the potential value of community information directed to other businesses, such as medical equipment suppliers, from which recipients of the cash benefit are likely to purchase services.

Due to their opposition to the cash program, Arkansas did not expect agencies providing traditional Medicaid personal assistance to be a major source of referrals for IndependentChoices. Thus, these agencies were not included in the community information campaign, even though they served a large number of potential participants through a variety of programs including homemaker and meals programs, as well as personal care.

Later, Arkansas asked providers of traditional services to refer potential participants. The traditional providers eventually referred a few cases to IndependentChoices. The referrals were people whom the agencies could not serve satisfactorily in the traditional

program, either because the clients were disgruntled with the services they received or because they lived in remote areas and were thus costly to serve.

Nor did IndependentChoices ask advocate organizations to become involved in the community information campaign. The fact that the major advocates for the elderly in Arkansas are the Area Agencies on Aging (AAAs) explains why advocates for the elderly were not approached as part of the community information campaign. Arkansas also did not approach advocate organizations for adults with disabilities as part of the community information campaign. As explained in Chapter II, before planning for the demonstration was complete, advocates for adults with disabilities had become less enthusiastic about the cash program. However, the state did approach Independent Living Centers to invite them to respond to the solicitation to provide counseling/fiscal services, and one did submit a bid.

B. Centralized Marketing Effort

Under IndependentChoices, the centralized outreach effort primarily involved direct marketing to consumers eligible for Cash and Counseling. It also involved informing the community through public service announcements and newspaper articles.

In IndependentChoices, DAAS took primary responsibility for the centralized marketing effort, with help from consultants hired by the National Program Office for Cash and Counseling. In addition, the marketing campaign was informed by the result of a survey of recipients of PAS, conducted by researchers at the University of Maryland. One of the consultants led focus groups of PAS recipients and their caregivers early in the planning for IndependentChoices. The focus groups were designed to improve understanding of the facets of the Cash and Counseling model that were attractive and unattractive to PAS recipients in Arkansas. The results from the focus group also informed the development of the questionnaire for the survey, which involved telephone interviews with a randomly selected sample of over 350 PAS recipients from across the state of Arkansas. A key finding of the survey was that interest in a cash program did not vary with the age of the consumer (Simon-Rusinowitz et al. 1997). Finally, a social marketing consultant helped to plan the marketing campaign, including brainstorming with state staff, and participated in a press briefing.⁶ State program staff felt that brainstorming with the marketing consultant was very helpful. For example, the idea for the focus groups with professionals came out of the brainstorming session.

The brunt of the day-to-day marketing effort fell upon the small staff at the state program office. As marketing began, the state-level professional staff for

⁶ Social marketing focuses on generating interest in social programs.

IndependentChoices consisted of the program administrator, who also was responsible for the Alternatives program, and two other full-time staff, both of whom had other program responsibilities within IndependentChoices. The assistant director for DAAS also devoted a substantial amount of time to IndependentChoices, despite her many other responsibilities. While the small state program staff had a “can-do” attitude and devoted a great deal of their time to marketing, they were unable to support a sustained marketing campaign while fulfilling their other duties. IndependentChoices did not have sufficient funding to hire the additional staff needed for a sustained, full-scale marketing campaign.

The marketing campaign began with a direct mailing of a letter from the governor of Arkansas to every person receiving Medicaid PAS at that time. The letter explained the program, enclosed a copy of the brochure with the tear-out postcard, and listed a toll-free telephone number (for the state offices of IndependentChoices in Little Rock) to call for more information.

The response to this mass mailing was overwhelming. Soon the toll-free number was flooded with telephone calls from those who had received the letter, as well as from others who had learned about the program through other means. While a number of callers were eligible for the cash program, others were not eligible for either Medicaid or personal assistance. Some had confused the Medicaid program with the Medicare program, and they were eligible only for the latter. Others were eligible for Medicaid but not for personal assistance. Some callers had expectations that could not be fulfilled and became angry.

One senior member of the program staff reported that an early edition of the brochure had not adequately explained the meaning of personal assistance. This may have led some people who were not recipients of Medicaid PAS to believe that the state was going to provide them with assistance with their housework and may explain some of the calls to the toll-free number from people who were not eligible. In light of this experience, the brochure was reworded to carefully define personal assistance.

The marketing campaign continued throughout most of the demonstration, relying on both direct mailings and public service announcements. A variety of mailings were sent. Some months after the initial governor’s letter, another letter was sent from the governor to those who had recently become recipients of Medicaid personal assistance and who therefore had not received the initial letter. Many months later, a letter was sent to all recipients of Medicaid personal assistance who had not yet elected to participate in IndependentChoices; this letter described the program’s successes and suggested that the recipient might want to reconsider participation. It enclosed news clippings with success stories about IndependentChoices. During the 1999-2000 holiday season, yet another letter was sent to all demonstration participants, thanking them for their participation and asking that they consider referring others to the program. Some did so, and most of those who responded referred a couple of people.

The holiday letter thanking consumers for their participation was sent to members of the control group, as well as to those receiving the cash benefit. Direct mailing to control group members proved to be problematic as a number of them called the state program office, asking when they were going to be allowed to participate in the cash program. Staff time was required to respond to these calls, and program staff were not able to promise that the cash benefit would be available to control group members by a certain date. Some had been angered earlier by their assignment to the control group, and the letter rekindled their anger.

In addition to direct mailings to beneficiaries, Arkansas relied on public media to reach potential participants for the cash program. Press briefings were held for print media, and several newspapers published stories about IndependentChoices. With the assistance of the consultant provided by the National Program Office, public service announcements were prepared and distributed to radio and television stations throughout Arkansas.

C. Lessons about Outreach

In Arkansas, direct mailings to recipients of Medicaid PAS appear to have been the most effective approach to generating enrollments. State program staff consider the direct mailings to have been much more cost-effective in generating enrollments than the public service announcements. Perhaps because personal assistance was carefully defined in later direct materials, state staff report that a larger proportion of those calling the toll-free number after later mailings were eligible for IndependentChoices than were those calling after the initial governor's letter. In contrast, public service announcements generated a lot of interest in the cash program, but many of those interested proved to be ineligible. State staff viewed newspaper articles as more cost-effective than public service announcements in generating enrollments but less cost-effective than direct mailings. They reported, however, that copies of newspaper articles were useful additions to direct mailings; the articles often personalized the program by including pictures of cash recipients. Overall, the Arkansas experience suggests that direct mailings may be more cost-effective than other means of outreach because they can be targeted to eligible individuals and because they can include *precise* information about the program, thereby helping to limit inquiries from people who are ineligible for the program.

It is difficult to judge the potential value of a localized community information campaign from the Arkansas experience. Clearly, direct marketing was much more effective in Arkansas in generating referrals. However, the community information campaign did generate initial interest in participation in IndependentChoices. Moreover, Arkansas identified a promising venue for community information efforts--businesses, such as pharmacies, providing services for which the cash allowance was likely to be spent.

Finally, the difference in the success of the local community information and marketing efforts in Arkansas may be due, at least in part, to the particular circumstances that prevailed there. First, the six-month lag between the initiation of the community information campaign and operation of the cash program probably blunted the effect of providing information to the community. Second, Arkansas faced a major obstacle (which other states might not face) in that many of the providers of traditional PAS were opposed to the cash program and also were the chief advocates for the elderly.

The Arkansas experience also suggests the importance of adequate staff time for community information and marketing efforts. While the six-month lag between the initiation of community outreach efforts and program operations was unintended, it probably permitted Arkansas to devote more effort to providing information to the community than would have been the case had enrollment begun shortly thereafter. Arkansas would have needed substantially more staff to simultaneously implement major community information, marketing, and enrollment efforts. After marketing began, the outreach/enrollment nurses were overwhelmed with the cases generated when the cash program was announced (via the governor's initial letter) to the entire stock of current Medicaid PAS recipients. Clearly, they did not have sufficient time to inform the community about the program at the same time that they were enrolling consumers. Nor did senior program staff have time to devote to community information efforts in the early months of operations of IndependentChoices; their time was taken up with resolving the inevitable problems that arise in the shakedown phase of a new program, and they were also responsible for implementing the centralized marketing efforts. Moreover, although they devoted a substantial proportion of the time to marketing, it was not possible for them to implement one marketing initiative while planning another. The lesson is that very substantial staff resources are required for the sustained community outreach and marketing efforts that may be required to enroll a large caseload in a relatively short period of time. Next, in Chapter V, we consider enrollment procedures under IndependentChoices.

V. ENROLLMENT

Enrollment in Arkansas' IndependentChoices program began in December 1998 with a flurry of activity. Following the mailing of the initial letter from the governor to current recipients of Medicaid personal assistance services (PAS), the number of people expressing interest in the cash program overwhelmed the program's capacity to verify eligibility for Medicaid PAS and to enroll those who were eligible.

In this chapter, we describe the enrollment process (including eligibility verification) in Arkansas and discuss the features of the program that were most attractive and unattractive to potential participants. We then draw some lessons about designing effective enrollment procedures for a cash benefit program.

A. The Enrollment Process in Arkansas

Arkansas implemented a centralized process for the initial steps of enrollment--checking eligibility for Medicaid PAS and responding to initial inquiries from interested consumers and their families. The rest of the enrollment process was decentralized, with nurses equipped with computers operating out of the four quadrants of the state.

1. Initial Interest and Eligibility

The state established a toll-free telephone number at the IndependentChoices offices in Little Rock to respond to initial inquiries of interest and to check callers' eligibility for Medicaid PAS. This telephone number was provided in outreach materials such as letters, brochures, and public service announcements. The people staffing the telephone line were knowledgeable about IndependentChoices and able to answer callers' questions. In addition, they could determine whether a consumer was eligible for Medicaid PAS. The eligibility criteria were (1) eligibility for the Arkansas Medicaid program, (2) need for assistance with at least two activities of daily living, and (3) physician's prescription for personal assistance.

The state established a database that listed all Arkansans eligible for Medicaid and indicating whether each was a current recipient of PAS. When someone called the toll-free number and expressed interest in enrolling in IndependentChoices, the person staffing the toll-free number could check the database during the telephone call to determine the caller's current eligibility status. If the potential participant was receiving PAS, a member of the central enrollment staff was able to confirm that fact while the caller was still on the telephone. For those who were eligible and interested, the state staff also collected

contact information to be forwarded to the outreach/enrollment nurse in the relevant region of the state.

The procedures were slightly different for Medicaid beneficiaries who were not current recipients of Medicaid PAS. While the person staffing the toll-free number was able to confirm Medicaid status during the initial telephone call, it was also necessary in such cases to establish the need for personal assistance with at least two activities of daily living and obtain a physician's prescription before proceeding with enrollment in the cash program. Medicaid beneficiaries who were not current recipients of PAS could be referred to a traditional home care agency, or the cash program's outreach/enrollment nurses could conduct an in-person assessment of need for personal assistance, develop a care plan from that assessment, and contact the consumer's physician for a prescription. Since several weeks almost always elapsed between the time a beneficiary contacted the cash program and his or her first cash payment, referral to a home care agency was appropriate when the beneficiary had no other source of immediate care.

The Medicaid database used to assess eligibility for IndependentChoices was updated frequently. While doing so was labor intensive, ready access to information on Medicaid and PAS status greatly increased the efficiency of eligibility checking. For most current recipients of PAS (except those enrolled in PAS shortly before they called to ask about the cash program), the database eliminated the need for off-line checks and return telephone calls.

Arkansas briefly closed enrollment to those who were not already receiving PAS. In response to the possibility that a cash benefit would induce demand for services (the so-called "woodwork effect"), the terms and conditions of the demonstration specified that the ratio of new to continuing PAS recipients in IndependentChoices was not to exceed the comparable historical ratio for the PAS population generally. When the ratio was reached, Arkansas closed enrollment to those not already receiving PAS and referred them to traditional services.

2. Enrollment

After initial interest and eligibility had been established, the remaining steps in the Arkansas enrollment process were decentralized. The four outreach/enrollment nurses used computers purchased by the state. (An additional person, not a nurse, was later hired to work out of Little Rock to "sweep up and catch up.") The IndependentChoices offices in Little Rock sent contact information weekly to the homes of the outreach/enrollment nurses, as attachments to E-mail messages. This process required training to increase the nurses' computer literacy, but it permitted efficient transfer of the enrollment information already captured in the initial telephone call.

When the outreach/enrollment nurses received the name of an interested consumer, they began to prepare for a visit to his or her home. They first telephoned the consumer (or a family member or friend whose name was given as a contact). One purpose of this telephone call was to provide information about the IndependentChoices program. The program is complex, and the nurse's telephone call provided an opportunity to reinforce what the consumer (or family member) already knew about the program and to respond to any questions the consumer might have. During these initial calls, the nurses stressed a key aspect of the cash program--the possibility of choosing a person to hire as a caregiver. They also stressed that participants in the cash program did not lose their Medicaid benefits, nor were they required pay taxes on the cash benefit since it was provided in lieu of PAS.

The second purpose of the nurse's initial call was to better understand the potential participant's reason for interest in the cash program. To develop such an understanding, outreach/enrollment nurses asked questions about receipt of Medicaid PAS, such as whether the potential participant had ever received services from a home care agency, whether he or she did so currently, and if not, why not. Many potential participants were interested in the cash program because they were dissatisfied with the agency home care services they had received or because agency attempts to find workers for them had been unsuccessful. This understanding not only helped the nurse to assess how the cash program might benefit a potential participant, but also helped prepare for the development of his or her cash management plan, for example, by suggesting uses of the cash benefit that might be of particular interest.

The final purpose of the initial call from the outreach/enrollment nurse was to schedule a home visit. Every effort was made to schedule such visits at a time when potential paid caregivers and representatives could be present. The nurses asked consumers to invite family members or friends who were important in their lives or who helped with day-to-day decisions or meeting their needs. Case Example V.1 relates the story of one family getting together to consider the cash program.

Case Example V.1: Family Participation in the Enrollment Visit

When the outreach/enrollment nurse called a daughter to arrange for her presence at a home visit, the daughter indicated that other brothers and sisters also wanted to hear about the cash program. On the day of the visit, the nurse reached the house, located down a country road, and had difficulty finding a place to park because of all the parked cars. Upon entering, she found that eight brothers and sisters had gathered at their mother's home.

Before a home visit to a consumer who was a current home care recipient, the outreach/enrollment nurse called the consumer's home care agency and requested a copy of his or her current care plan (via facsimile). Using the information on approved hours from this care plan and the agency-specific discount rates established by the state, the

nurse calculated the amount of the cash benefit that the person would receive if assigned to the treatment group. A separate discount rate was applied to the hours in the care plan that the nurse developed for those new to PAS. The consumer received information on the amount of the benefit at the time of the home visit. Although the cash benefit was calculated on a daily basis, most consumers were used to a monthly budget. Therefore, the outreach/enrollment nurses cited a monthly amount (assuming a 30-day month) but indicated that the amount would vary slightly, depending on the number of days in the month.

During the home visit, the outreach/enrollment nurse explained IndependentChoices to the consumer and his or her family and friends. To do so, the nurse used a set of show cards. These were written in simple English, using a question-and-answer format, with pictures added for interest. (Appendix B presents these show cards.) The nurse also read the five-page consent form for the demonstration, stopping after each section and asking if there were any questions about that section. The nurse also cited the amount of the cash benefit that an individual consumer would receive (as explained in the previous paragraph). Finally, the nurse helped the consumer and his or her family calculate how many hours of care they could buy with the cash benefit at different wage rates (also taking into account payroll taxes and unemployment insurance).

In Arkansas, representatives were selected during the enrollment process. During the home visits, the outreach/enrollment nurses helped the consumer consider whether a representative might be needed. Chapter VII discusses the role of representatives in IndependentChoices.

At the conclusion of the home visit, the outreach/enrollment nurse determined whether the consumer had decided to enroll in the demonstration. If so, the nurse completed an enrollment form, which was transmitted to the central program office in Little Rock. Once a week these enrollment forms were transmitted electronically to the offices of the evaluation contractor. When a form was received, the evaluation contractor attempted to complete a baseline interview for that consumer. After the baseline interview was completed for a given consumer, the evaluation contractor randomly assigned him or her to the treatment group (to receive the cash benefit) or to the control group (to remain in traditional personal assistance). The evaluation contractor notified the state of each consumer's random assignment, and the state sent a letter to the consumer notifying him or her of the result.

The letter to control group members encouraged them to contact the state program office if they needed assistance in obtaining traditional personal assistance services. When a control group member called for assistance, the state program office often referred him or her to a traditional agency. When the state program office made such a referral, it also forwarded a copy of the care plan developed by its outreach/assessment nurse. However, the traditional agencies were not required to base their care for control group members on the care plans (if any) they received from IndependentChoices. State

program staff were of the opinion that traditional agencies generally developed their own care plans in such circumstances.

B. Attractive/Unattractive Features of the Cash Program

Consumers found some features of IndependentChoices attractive, others unattractive.

1. Attractive Features

IndependentChoices staff reported that consumers found the ability to hire relatives to be the single most attractive feature of the cash program, for several reasons. Perhaps the primary reason was that hiring relatives and friends provided the consumer with security and peace of mind. Most people are wary of strangers coming into their homes. Many of those interested in the cash program had tried home care agency services in the past but had dropped them due to lack of security. Case Example V.2 is the story related by one consumer whose concern about security led to interest in the cash program.

Case Example V.2: Security Problems with Traditional Services

A home care client had a treasured collection of bottles. Her aide admired the collection and, one day, asked if she would be willing to sell one of them. The client refused, indicating that she was unwilling to part with any of them. Shortly thereafter, the client noticed that the bottle that the aide had admired was missing. Several new bath towels were also missing. When confronted, the aide denied knowledge of the missing items. The client called the agency and said that, while she could not prove it, she was sure the aide had taken them. The agency representative replied that another aide would be sent, but if the client could not get along with that person, then the agency would discontinue all services. In response, the *client* discontinued all agency services.

The staff of IndependentChoices also reported that care by family members and friends as attractive because personal assistance is intimate. It can be demeaning to have a stranger strip you to give you a bath. Case Example V.3 talks about the intimacy of personal assistance.

Case Example V.3: Intimacy of Personal Assistance

A home care aide had been told that her new client would have to get to know her before she would allow the aide to bathe her. One day, the aide reported to her supervisor that she was very pleased because the client had finally allowed the aide to bathe her. "But she still didn't take her underwear off."

According to the staff of IndependentChoices, other consumers found hiring family members or friends attractive because they had found home care aides to be unreliable. These consumers and their families complained that they never knew whether the aide would come as scheduled. If the aide did not come, the consumer went without needed care, such as a bath, or family members rearranged their schedules to provide the care. Families sometimes have been providing care themselves for years in order to ensure reliable care.

The care that family members and friends provide can be more flexible than care from a home care agency. This flexibility may involve scheduling. For example, many agencies do not “do evenings or weekends.” The flexibility may involve services that home care agencies do not provide. For example, Medicaid regulations do not allow home care agencies to transport their clients.⁷

Family members and friends who live close to the consumer may be able to devote a larger proportion of paid time to actual care than can home care agency employees. This is because the billed time for home care agency aides often includes travel time; perhaps only 20 minutes per hour is actually devoted to patient care.

Finally, the staff of IndependentChoices reported that consumers found it attractive to be able to pay something to those family members and friends who have been helping them--often for many years--even if the amount of the payment did not compensate them for all they did. As one outreach/enrollment nurse put it, “They [consumers] feel they are giving something back to those that help them out of love--a token payment but still something.”

2. Unattractive Features

According to program staff, consumers found several features of IndependentChoices unattractive. For recipients of state plan PAS who were also receiving services through the ElderChoices waiver, the fact that the latter program was not being cashed out made participation in IndependentChoices less unattractive. (As discussed in Chapter II, ElderChoices is for community resident Medicaid beneficiaries who qualify for an institutional level of care. It is designed to operate in conjunction with PAS.) A key advantage of IndependentChoices--that no stranger need come into the home--was often moot for ElderChoices participants, since an agency aide might continue to come under that program. Moreover, many home care agencies provided both PAS and ElderChoices services and sent a single individual to care for a client participating in both. In such a situation, it was difficult for consumers considering the cash program to

⁷ Some agencies had been allowing aides to transport clients to a doctor’s office, but Arkansas began to strictly enforce these regulations some months before our site visit.

decide which tasks the aide should continue to perform and which someone hired with the cash benefit should take over.

Perhaps most important, consumers receiving services under both ElderChoices and PAS often received a majority of their services from the former. As a result, the amount of the cash benefit (based on PAS hours) might be low, and participation in the cash program was less attractive. This situation arose because the hourly rate paid by the state to home care agencies for services rendered under ElderChoices had, at one time, been lower than the rate paid for PAS, and Medicaid regulations had stipulated the provision of all allowable ElderChoices hours *before* the provision of PAS hours in order to minimize costs. Even if consumers wanted to disenroll from ElderChoices to increase their cash benefit, they were discouraged from doing so by the staff of IndependentChoices who feared “getting cross-threaded with the other program.”

Another unattractive feature of the cash program, as reported by staff of IndependentChoices, was the paperwork required of an employer under state and federal law. The state unemployment office required that a participant in the cash program give limited power of attorney to the fiscal intermediary to act on the participant’s behalf. Some people were very concerned about granting even a limited power of attorney; a few feared that the state would be able to take possession of their home if they granted it. Other potential participants were concerned about the burden of completing federal payroll tax forms. Almost all participants in IndependentChoices availed themselves of the services of the fiscal intermediary (provided without charge to participants) for the preparation of payroll taxes. The availability of fiscal services without additional charge seems likely to have gone far in ameliorating the unattractiveness of the paperwork required in the cash program in Arkansas.

IndependentChoices was also less attractive to those clients who liked their current home care aide, according to program staff. Few, if any, participants in the cash program in Arkansas hired their agency aides. Since agencies did not forbid aides to accept such positions, it may be that the jobs were not sufficiently attractive. Many aides probably wanted to work more hours than a single consumer could afford to purchase with the cash benefit. The average cash payment in Arkansas would not cover even half-time work (assuming an hourly wage of \$7.00 an hour). Only late in the demonstration did mechanisms begin to develop to help workers hired with the cash benefit find positions working for other cash recipients.

Still other consumers found the cash program less attractive due to restrictions placed on the uses of the cash, according to staff of IndependentChoices. Some consumers were disappointed that the full amount at which the discounted care plan was cashed out (\$8.00 per care plan hour) could not be paid as wages. After providing for payroll taxes, the maximum wage possible was about \$7.25 an hour (unless the number of hours was reduced). Others had hoped to use the cash for purchases unrelated to their

personal assistance needs and were disappointed when the restrictions on the uses of the cash were stressed during enrollment.

According to program staff, the state's restriction on hiring spouses was one particular restriction on the uses of the cash benefit that was unattractive, especially for elderly men. Such men were used to having their wives provide their personal assistance--sometimes very intimate assistance--and they definitely did not want a stranger doing so.

A final unattractive feature of IndependentChoices was random assignment. Staff of IndependentChoices reported that some consumers were reluctant to spend the effort to assess the cash program's effectiveness for themselves because they felt that this effort would be wasted if they were assigned to the control group. Case Example V.4 elaborates on the responses to assignment to the control group. Random assignment was required by the evaluation and would *not* be a feature of an ongoing program.

Case Example V.4: Assignment to the Control Group

Some people became quite angry at being assigned to the control group. They would call the toll-free number and complain. A few asked to be allowed to repeat the baseline interview (for the evaluation), as they were convinced that they had been assigned to the control group because they had answered the questions "incorrectly." Notwithstanding the disappointment of some control group members, there is no evidence of tampering with random assignment.

C. Lessons Learned

Key lessons about enrollment from the Arkansas experience in IndependentChoices involve enhancing the efficiency of the enrollment process and providing information for consumer decision making.

1. Efficiency in Enrollment

Arkansas learned to enhance the efficiency of the enrollment process by reducing paperwork, smoothing work flow, minimizing travel, and reducing multiple home visits for a single case almost to the point of eliminating them. Paperwork was reduced by printing forms on no-carbon-required paper, which eliminated the need to complete an extra copy of each form to leave with the consumer. Staff smoothed their work flow by scheduling visits over somewhat longer periods. Initially, the outreach/enrollment nurses expected to conduct the home visits for all cases shortly after receiving the referrals. Gradually, however, they realized that most of the referrals did not involve emergency situations and that they needed to make their own work more efficient by consolidating their appointment schedules and reducing travel time. Travel could be reduced by grouping visits to

consumers who lived near one another but at some distance from the home of the outreach/enrollment nurse. One nurse reported calling consumers in distant locations to tell them that she would be visiting them shortly when in that area, then waiting a week or two before scheduling a date for the visit to see if she received other referrals for people living in the area. In contrast, visits to those who lived relatively close to the home of the outreach/enrollment nurse did not have to be grouped since the travel time for these visits was minimal.

Arkansas also learned that having family members and friends at the initial home visit was important to an efficient enrollment process. Their presence was not difficult to arrange with advance scheduling and greatly reduced the need for multiple home visits during enrollment. If the consumer had not yet discussed the program with a potential caregiver, the outreach/enrollment nurse would ask that they do so; she would then call back in a day or two to schedule the home visit. One nurse reported that, in all but two of her cases, arranging for family members and potential caregivers to be present at the initial home visit eliminated the need for additional visits to meet with family members.

2. Information for Decision Making

Several important lessons from Arkansas' experience with IndependentChoices involve the types of information that consumers need and the best ways to provide it.

Drawing on their understanding that the average Medicaid recipient in Arkansas reads at a third-grade level, state program staff knew that it was important to provide information in ways that people of limited reading ability could understand and to frame answers to their questions in terms that they found meaningful. Arkansas developed show cards, with a simple question-and-answer format, to explain the cash program during the home visit. The questions were those commonly asked about the demonstration and evaluation, and the answers were based on initial experience with IndependentChoices and framed in language that consumers seemed to understand. The state also provided many opportunities for oral communication during the telephone calls to the statewide toll-free number and to the outreach/enrollment nurse, as well as during the enrollment home visits. When the material was difficult--for example, the consent form to participate in the demonstration and evaluation--the nurse reviewed these materials with the consumer, reading the material section by section and pausing after each section to respond to questions.

Arkansas also learned the value of family members and friends as part of an effective strategy of providing information to the consumer. If family members and friends had participated in the home visit, they were often able to answer questions that occurred to the consumer after the outreach/enrollment nurse left. Sometimes, family members and friends were able to expedite the home visit by offering to explain something to the consumer after the visit, saying, for example, "I understand that; I'll explain it to you later."

A critical lesson of IndependentChoices was the need to combat misinformation. Action was necessary to counter a common misunderstanding that the cash benefit would be treated as income for the purposes of determining eligibility for means-tested federal programs (such as Supplemental Security Income and Medicaid) and for determining federal tax liability. Unaware that several federal regulations had been waived for the demonstration, some in the community--often aides employed by home care agencies--apparently were advising Medicaid beneficiaries against participation in the cash program on the grounds that they would lose eligibility for means-tested programs and be required to pay taxes on the cash benefit. This misunderstanding led some consumers to lose interest in participation. As one outreach/enrollment nurse put it, "Say IRS, and they get scared." Given the level of beneficiary concern, outreach/enrollment staff needed to take an active stance, stressing even in their initial telephone call that participation in IndependentChoices would not affect eligibility for means-tested programs and income tax liability. Over time, there were fewer incidents of misinformation apparently spread by home care agency staff members. However, the opposition of home care agencies to IndependentChoices had not been fully resolved at the time of our visit in spring 2000.

VI. CASH PLANNING AND MANAGEMENT

After a demonstration participant was assigned to the cash program, state IndependentChoices staff notified the appropriate counseling/fiscal agency to begin providing service, starting with the development of the cash management plan. This chapter describes the processes that the counselors and fiscal agents (known to the consumers as “bookkeepers”) used to help the consumer develop the cash plan and manage the cash benefit.

A. Developing the Cash Plan

A counselor received the name of a new consumer by E-mail from the state office. The information provided was limited to demographic and contact information and the number of personal assistance hours that were to be cashed out. The counselor then called the consumer to schedule an initial home visit to train the consumer to develop the cash management plan.

1. Pre-Visit Telephone Call

The counselors considered the pre-visit telephone call very important, for several reasons. First, it was an opportunity to identify any resistance to participation that had arisen since enrollment. Counselors reported that current home care aides sometimes discouraged consumers from participating in the cash program even after they had enrolled. Some aides reportedly provided inaccurate information about the cash program or emphasized how hard it might be to act as an employer. Counselors tried to correct misperceptions and address concerns. They usually could do so if the consumer was discouraged but was at least willing to talk with the counselor.

Second, the pre-visit telephone call allowed the counselor to review the details of the cash program and to discuss how the consumer might use the cash and what uses were allowable. If the consumer wanted to hire someone, the counselor asked whether a potential worker had been identified. If the consumer had identified a potential worker, the counselor encouraged the consumer to start discussions with worker. If no potential worker had been identified, the counselor encouraged the consumer to think about how a worker might be found.

Third, during the pre-visit telephone call, the counselor encouraged the consumer to have others attend the initial training meeting. If a representative had been selected, counselors noted that he or she was expected to attend. Similarly, if a worker had been selected, the counselors asked that he or she attend the initial training meeting. In

addition, other family members who might be providing help with personal assistance or decision making were invited to this meeting.

The counselors reported that, as they gained experience, they became more adept at preparing for the initial training visit during the pre-visit telephone call. As a result, their initial training visits became more productive and efficient, thereby reducing the need for return visits.

2. The Initial Training Visit

At the initial training visit, the counselor focused on developing the cash plan, training the consumer on his or her employer responsibilities, and, if a worker was available, completing the hiring paperwork. In doing so, the counselor used a training manual to orient the consumer to the program. The manual included all the program forms and was given to the participant for later reference.

Developing the cash plan involved discussing the best uses of the cash benefit for that consumer. The discussion opened with consideration of the tasks with which the consumer wanted assistance and how many caregiver hours might be required to accomplish those tasks. If a worker was to be hired, the discussion included how much the hourly wage might be after allowing for payment of the required taxes and unemployment insurance and how many paid hours the cash benefit could cover. Other allowable uses of the cash were also discussed. While almost all consumers hired a worker, in a few cases the consumer's family preferred to provide assistance without pay and use the cash to pay for nonprescription medications or other health care supplies that the family had been paying for privately. Consumers might also decide to save some of the cash benefit for a more expensive item, such as a washing machine.

The counselors also discussed other public programs for which the consumer was eligible and that might provide additional resources to address the consumer's needs (such as Medicaid for some types of equipment). Counselors also listed places to buy things inexpensively.

While counselors had available the listing of resources that the outreach/enrollment nurses had developed during the community information campaign, neither counseling/fiscal agency maintained a comprehensive, local resource handbook--a listing of local resources (such as nonprofit agencies and programs) throughout their service area to which consumers might be referred. Without access to such a handbook, counselors may not have been as aware of available resources (especially resources for areas of the state with which the counselors were not personally familiar) as staff of traditional agencies with case management responsibilities for clients in a local area.

If the cash management plan included hiring a worker, a back-up plan was also developed. This plan specified how the consumer would receive personal assistance if the worker did not come when scheduled.

At the end of the planning process, a form--the formal cash plan--was completed listing the uses of cash that had been agreed upon. Often, cash planning did not proceed far enough at the initial training visit to complete this form. Rather, several telephone contacts over several weeks might be required to complete the cash-planning process.

Sometimes, additional time was required to seek state approval for a use of the cash requested by a consumer. If all of the uses of cash were on the list of approved uses compiled by the state, the counselor could approve the cash plan. As indicated in Chapter II, uses of the cash benefit not on the list required state approval. (This issue is discussed further in the next section).

Since most consumers wanted to hire a worker, much of the content of the initial training visit focused on the consumer's responsibilities as an employer. Much emphasis was placed on the consumer being "the boss." Counselors would stress, "Consumer direction means the consumer is in charge." They did so in front of workers--especially when the worker was a family member--to stress the importance of this basic tenet of consumer direction. Case Example VI.1 explains this process in the words of one counselor.

Case Example VI.1: Teaching That the Consumer Is the "Boss"

"I want them and their family member to hear and take the responsibility seriously. I treat [the hire] just as if it will be with a stranger, even though the family member who will be hired is sitting right there. I go through the whole program, explaining that some of it may not apply (such as the criminal background checks, and checking references) but I say, 'There may be a time you'll want to hire a back-up worker.' I tell them, 'You are the boss, you tell them how you want it done.' I train on safety issues, having emergency numbers available, having the information an ER would need. Everything."

The counselors discussed with consumers the need to (1) develop a specific job description that would explain clearly what was expected of the worker, and (2) give the worker feedback about his or her performance. They also discussed the consumer's prerogative to terminate a worker who was not performing satisfactorily, telling consumers, "You are able to fire your worker if necessary because you are the boss." The counselors emphasized that they would check with consumers monthly to see whether they were satisfied with their worker's performance.

Counselors also reviewed the consumer's fiscal responsibilities as an employer. These responsibilities include keeping track of worker hours, completing and signing worker time sheets, and promptly sending the time sheets (twice a month) to the

counseling/fiscal agency for payment. Deducting and paying the payroll taxes and unemployment insurance is also an employer responsibility. All consumers needed a basic understanding of the payroll tax and unemployment insurance requirements, even if they delegated responsibility for paying payroll taxes and unemployment insurance to the counseling/fiscal agency.

Finally, if the cash management plan had been agreed upon and the potential worker was available, the hiring paperwork could be completed during the initial training visit. This paperwork included the forms necessary to initiate payroll tax deductions (such as the W-4 form for federal taxes) and payment of state unemployment insurance.

As counselors gained experience, the initial training visit became more efficient. The Division of Aging and Adult Services (DAAS) had provided the counseling/fiscal agencies with a prototype cash management form. The agencies streamlined the prototype form based on early experience, and counselors found that the revised documents were easier to use. Perhaps more important, the counselors became more proficient in explaining the cash program to consumers. They learned which aspects of the program were difficult for consumers to understand and what types of explanation consumers needed and found most helpful. Moreover, counselors learned not to “overexplain.” For example, they learned not to explain the state’s formula for arriving at the amount of the cash benefit. Instead, they cited the actual monthly amount (for 30-day and 31-day months), then offered to show the consumer how that amount had been determined if the consumer wanted to know.

One aspect of the original plans for the initial training visit--sending an advance copy of the consumer-training manual--did not work well and was dropped. The plan had been to send these manuals out before the visit so that consumers could familiarize themselves with the material before the counselor arrived. However, many consumers found material in the manual confusing or the volume of material intimidating. Others mislaid the manual before the counselor visit. After these problems surfaced, the procedures were revised; thereafter, counselors gave the manual to consumers during the initial training visits.

3. Nonroutine Requests for Uses of Cash

Arkansas maintained a list of approved uses of the cash, with state approval required for purchases not included on the list. The state was flexible with respect to approved uses of the cash. It encouraged the counselors to be creative in trying to accommodate consumer wishes, as long as the use of the cash related to the consumer’s personal assistance needs. Some counselors would have liked the authority to decide whether a purchase was allowed to avoid having to tell the consumer, “I have to check on that.” On the whole, however, the process worked well, and counselors appreciated the state’s flexibility.

Three issues about nonroutine uses of the cash are noteworthy. First, counselors noted the importance of a shared perspective between outreach/enrollment nurses and counselors on the appropriate uses of the cash. Some consumers tried to persuade the counselors to approve a questionable use of the cash by reporting, "The nurse said that I might spend the cash allowance on that." One consumer said, "She said I could use it for anything but gambling." Joint meetings between the outreach enrollment staff and counselors helped to foster a common understanding of appropriate use of cash and to limit the number of instances in which counselors had to disapprove a use of cash that consumers reported they had been told was allowable.

Second, even when the cash program would not cover a requested purchase, counselors were allowed to work with the consumer and his or her family to identify a "switch." That is, counselors worked to identify a personal-income purchase that could be included in the cash program, thereby freeing personal income for the purchase of the original request. Such a switch was made, for example, for an elderly woman who was concerned about burdening her children with her funeral expenses and who had wanted to purchase burial insurance under the cash plan.

Third, the cash program was sometimes used, with state approval, to pay expenses in an emergency situation. These situations did not seem to arise as a result of misuse of the cash benefit already received, but rather as the result of dire poverty. For example, moving costs were allowed when a consumer needed to move to another town to live with a daughter, and a rent payment was allowed to prevent another consumer from being evicted. The state determined whether consumers would have to pay back the money for emergency purchases from future cash benefits, and most consumers were required to do so.

Arkansas established a special revolving fund, called the Pot of Gold, that was held by the counseling/fiscal agencies. A sum of \$1,000 was advanced to each counseling/fiscal agency early in the demonstration. This money was to be used to help consumers in emergency situations or when there was a delay in processing the regular cash payment. The Pot of Gold was replenished as necessary as expenditures were made against it (with the entire advance of \$1,000 to be returned to the state at the end of the demonstration). However, one counseling/fiscal agency reported that the paperwork needed to track Pot of Gold payments was so onerous that it sometimes had advanced money from its own funds.

B. Uses of Cash

Program staff reported that almost all participants in the cash program hired a worker. Other common purchases with the cash benefit included health and personal assistance goods and adaptive equipment.

1. Hiring Workers

Why did almost all recipients of the cash benefit hire a worker? Could it be that counselors were “overselling” the idea of hiring workers? This may have been true to some extent, at least early in the cash program. Counselors were concerned initially that they and their agency were responsible--and might be held legally liable--if consumer safety or well-being suffered due to inadequate care.

This concern was misplaced, however. Under IndependentChoices, the counselor was responsible for helping a consumer identify and carry out his or her own wishes, but not for the consumer’s well-being, even if that was adversely affected by the consumer’s own decisions. A counselor who was concerned about consumer safety or well-being was to report those concerns to the state, which decided how to proceed. In such a situation, the state might (1) order intensive monitoring of the case to better assess the situation, (2) order problem solving to resolve it, or (3) mandate that a consumer return to the traditional program. Thus, final responsibility for solving problematic situations rested with the state of Arkansas, not with counselors or counseling/fiscal agencies.

On the other hand, perhaps it should come as no surprise that almost all recipients of the cash benefit hired a worker. After all, to be eligible for the cash program (as for Arkansas’ Medicaid personal assistance program generally), one had to be impaired in two activities of daily living--a relatively substantial level of impairment. While equipment and modifications of the environment can reduce the need for personal assistance, they are unlikely to eliminate the need for all assistance from another human being for consumers with that level of impairment. Moreover, the cash benefit was provided in lieu of the assistance of a worker. Thus, assistance from another person was the type of assistance with which many cash recipients were most familiar. In the few cases in which cash recipients did not hire workers, they still needed assistance. Their families provided this assistance without charge, freeing the cash benefit to be spent on other goods and services.

2. Other Types of Expenditures from the Cash Benefit

Program staff reported that other common uses for the cash benefit included health and personal care supplies, equipment, and services not covered by Medicaid. Many cash recipients purchased nonprescription medications and prescription medications not covered by Medicaid. (In Arkansas, three prescription medications are covered at a time under the Medicaid program unless an exception is applied for and granted. In the latter case, six are covered.) Other common expenses were adaptive equipment and supplies for incontinence and oxygen use. Some consumers also purchased dental care not covered by Medicaid. (For example, Medicaid coverage for dentures is limited in Arkansas.)

Some retailers allowed consumers to receive goods on credit knowing that IndependentChoices could pay them directly. Pharmacies and companies selling durable medical equipment--suppliers of the types of goods that were most commonly purchased with the cash benefit--were the most likely to do this. In at least one case, however, a furniture store extended credit, filling a medical order for a recliner and allowing the consumer to pay it off over time from the cash benefit.

Program staff reported that it was less common for consumers to use the cash benefit to make environmental modifications. The explanation may be the expense involved, compared to the amount of the average cash benefit in Arkansas. Even the relatively minor modification of having a ramp built could be quite expensive. Much of Arkansas is rural, and carpenters charge for their time to travel long distances. Some consumers did use the cash benefit to buy lumber and other supplies for their relatives to use in building a ramp.

Some of the uncommon uses of cash were quite creative. A woman who lives in a rural area and is homebound because of multiple sclerosis paid for an Internet connection. She already owned a computer and had telephone service. The Internet connection allowed her access to an online support group and to information about her condition.

Although most cash plan purchases were recurring, consumers could make one-time purchases. Examples of such purchases include the initial visit of an exterminator, a mattress, one trip to a beauty parlor for a haircut, a short period of paid care (three days) when an unpaid caregiver was having surgery, and replacement parts for household appliances. Payments of emergency expenses were also one-time purchases under the cash program.

Counselors reported that small amounts of money could sometimes make a big difference for consumers because their personal incomes were limited. One consumer's washing machine had been broken for six months for want of a \$20 part. The consumer used the cash benefit to purchase a replacement part, and the repair of the machine improved her personal hygiene and the cleanliness of her living conditions.

Under IndependentChoices, consumers could use up to 10 percent of their cash benefit at their own discretion to meet personal assistance expenses that arose during the month. A check for the 10 percent discretionary amount--typically less than \$40--was sent to consumers at the end of the month, unless the consumer directed otherwise. Consumers frequently used these discretionary funds for personal hygiene items such as soap, shampoo, and toothpaste. Having the funds to pay for even these small items helped some consumers feel less like a burden on their families.

3. Time to Receipt of Cash

Arkansas' goal was to have consumers complete a cash management plan and move from traditional services (if any) to consumer direction within 45 days of referral to the counseling/fiscal agency. The state set the maximum transition time to 90 days, although it took extenuating circumstances into account in enforcing this. A few consumers were able to move to consumer direction very quickly; the shortest time was five days. Some eventually dropped out of the cash program without ever completing the cash management plan and thus without ever receiving a cash payment. By spring 2000, the average time to receipt of cash from referral to the consumer/fiscal agency was 42 days.

Elapsed time between enrollment and receipt of the cash benefit was an issue partly because it affected the cost of IndependentChoices. Arkansas incurred costs for *both* traditional services and the monthly counseling/fiscal agency fee from the time consumers enrolled and were assigned to the treatment group until they began to receive a cash benefit (or disenrolled from the cash program).

Program staff reported that the major factor that influenced how rapidly (or even whether) the cash management plan could be developed was difficulty in identifying a worker to hire when there was no family member or close friend to fill this role. Consumers in this position (in Arkansas, roughly five percent of those assigned to the cash group) had to identify potential workers and interview them. Some consumers were not able to identify a worker and eventually withdrew from the cash program, generally going back to traditional services.

Having second thoughts about participating in the demonstration was also a major reason for delay in receipt of a cash payment, according to program staff. While most consumers participating in IndependentChoices were dissatisfied with the services they had received from traditional agencies, some liked their agency workers and had difficulty deciding to hire someone else in their stead. (As indicated in Chapter V, consumers in Arkansas hired their agency workers rarely if at all.) Physical illness also delayed the transition to cash, sometimes causing extensive delays. When consumers were in the hospital or recovering from an acute illness, they and their families were unable to work on completing the cash management plan. The state granted exemptions to the maximum of 90 days to transition to cash to a small number of consumers because they had a health crisis and were admitted to a hospital, then discharged to a nursing home or rehabilitation center.

Program staff reported that the consumer's attitudes and life experiences also affected the time to transition to a cash payment. Such attitudes and experiences included the consumer's level of comfort and experience with making decisions and with change, how comfortable the consumer had been with traditional agency services, how much experience he or she had in managing money, and whether the consumer had adjusted to

disability and to the need for help with personal assistance. All of these factors represented training issues, and the counselors had to be patient, providing support to the consumer and pacing the process to avoid overwhelming him or her, while keeping the 90-day time limit in mind. Finally, program procedures caused some delay in transitioning to cash.

Consumers could begin to receive cash at the beginning or at the middle of the month, so the transition might be delayed a few days, depending on the day in the month on which the cash plan was completed. In addition, the state was required to give notice to a consumer's current provider (if any) that traditional services were to be terminated. Originally, the state gave 30-day notice, but it shortened this to 10 business days (or 14 calendar days) when a problem arose with aides seemingly trying to persuade consumers to disenroll from the cash program.⁸ In addition, the counselors said that longer transition times sometimes reflected how well the counselors themselves were doing their jobs in training a person on consumer direction.

4. Changes to the Cash Plan

The cash management plan had to cover all expenditures from the consumer's cash benefit (except for the 10 percent discretionary amount). If the consumer wanted to buy something not listed on the plan, he or she had to call the counselor to see if a given use was already covered under another category and, if not, whether the purchase was allowable. If the use of cash was not already covered in the consumer's plan, the cash management plan had to be formally revised, although the required forms might not be formally signed until the counselor next visited the consumer. Such calls occurred often, and revisions frequently were required. Counselors completed the new cash plans and sent copies to the consumers.

Over time, the counselors learned to write the cash plans somewhat flexibly to cover more circumstances so that formal changes would be necessary less often. For example, they learned not to name a specific worker in the plan, but rather to list the tasks and the pay rate. Thus, a change in the identity of the worker did not necessarily require a change in the plan.

A revision of the cash management plan might also be required if the amount of the cash benefit changed following a change in the consumer's condition and a subsequent "event-based" reassessment and revision to care plan hours. Program staff reported that event-based reassessments and care plan revisions were uncommon, but that care plan hours were increased substantially in most of the cases with event-based reassessment.

⁸ Occasionally, a consumer would tell an aide not to come back before the termination notice arrived at the agency, causing the agency to blame the state for providing inadequate notice.

The approval process probably limited the frequency of event-based reassessments for several reasons. First, Arkansas Medicaid requires physician approval for every care plan, including those following an event-based reassessment. Second, if a proposed care plan called for a 10 percent (or larger) increase in approved hours, IndependentChoices required approval by the state program staff. Finally, Medicaid regulations required that any care plan calling for more than 64 hours of care a month be approved by the Medicaid utilization review office. In the uncommon cases in which event-based reassessment and care plan revisions were sought for cash program participants, the revised care plans generally called for more than 64 hours of care a month.

C. Payments and Taxes

The major fiscal responsibilities of the consumers in IndependentChoices were payment of expenses covered by the cash plans and submission of payroll tax forms and related documents for workers paid under these plans. Almost all consumers delegated these responsibilities to the counseling/fiscal agencies.

1. Payment

Twice a month, consumers submitted worker timesheets and check requests to the counseling/fiscal agency. The counselors checked each time sheet and request against the corresponding cash plan to see that the expenses involved were covered. Sometimes, the counselors found discrepancies. In such cases, the counselor telephoned the consumer to discuss the discrepancy. During such a call, the counselor would remind the consumer about the need to have spending match the cash plan and would ask whether the consumer's needs or situation had changed and whether the cash plan still reflected how the consumer wished to spend the benefit. If necessary, the counselor would revise the cash plan.

After the time sheets and check requests were approved, the bookkeeper cut checks and sent them to the consumers to pay their workers or for other expenses. Checks were also sent directly to vendors at consumer request.

Twice a month, the counseling/fiscal agencies also sent checks for the full amount of the cash benefit to the handful of consumers who chose not to delegate fiscal responsibilities to the agencies.

The bookkeepers at the two counseling/fiscal agencies had somewhat different responsibilities within the cash program and different levels of involvement with counselors and consumers. At the larger counseling/fiscal agency, the bookkeeper worked only for the cash program. She attended the weekly staff meeting at which the circumstances of various consumers were reviewed. She also was available to consumers by phone to

answer questions. (When asked to characterize the closeness of the relationship between the counselors and bookkeeper at this agency, a counselor responded, "Are you married? About that closely--constant and close.") In contrast, the bookkeeper at the other agency was responsible for maintaining the books for all of the programs offered by that sponsor organization--not just those for IndependentChoices. Counselors at that agency protected the bookkeeper's time as much as possible--for example, consumers were discouraged from speaking to her directly.

The counseling/fiscal agencies had relatively little problem with the timeliness of consumer submission of time sheets and check requests. One agency reported that only a handful of consumers (5 of almost 350) regularly failed to submit time sheets on schedule. The agency characterized this problem as no more serious than among its own employees.

Nonetheless, consumers and workers occasionally complained that they had not received their checks promptly. The counseling/fiscal agencies attributed these delays to consumer failure to submit time sheets promptly and to allow sufficient time for mail delivery of checks. The agencies worked to minimize these problems by reminding consumers of the need to submit time sheets and check requests on schedule so as to allow time for mail delivery. (Mail delivery typically took three to four days in Arkansas, even from one side of Little Rock to the other.) One agency sent all consumers a letter explaining how long to allow for mail delivery. The other worked with the local post office to revise the agency's mailing procedures so as to expedite delivery.

In an urgent situation, the counseling/fiscal agencies would cut a check for the consumer, even if the timesheet or check request came in late. The counselors would take information over the telephone from the consumer, complete a temporary time sheet or check request, and submit that to the bookkeeper for processing. In these circumstances, a consumer was required to complete and submit a signed time sheet or check request. When that was received at the counseling/fiscal agency, it was placed in the consumer's file in lieu of the temporary document.

Counseling/fiscal agencies made few errors in calculating the amounts of payments. Almost all consumer complaints about possible errors were resolved by reminding the consumer or worker of required deductions from payroll checks. On one occasion, a duplicate check was mailed inadvertently. That situation was readily resolved, as the consumer saved the duplicate check to give to the counselor who was scheduled to visit shortly thereafter.

Perhaps the most serious problem that arose with respect to fiscal performance involved cash disbursements. Arkansas' intent was that consumers receive no more than 10 percent of their monthly benefit as cash to be spent at their discretion. Quite apart from such cash disbursements, consumers were allowed to accumulate funds over time to save

for one-time purchases. Such purchases required approval under the usual procedures. The counseling/fiscal agencies erred for a number of months by disbursing any funds remaining at the end of the month, sending a check for that amount to the consumer. Consequently, some consumers received more than 10 percent of the benefit in cash. They did not have to declare a purpose for these cash disbursements, nor were they required to submit receipts for them. At the time of our visit, the state was taking action to ensure that funds over the allowed 10 percent were retained in such situations until the expenditure was authorized in the cash management plan.

2. Processing Payroll Documents

The adequacy of the performance of the counseling/fiscal agencies with respect to processing payroll tax forms and other payroll documents was mixed.

Initially, the counseling/fiscal agencies experienced some difficulty in obtaining federal tax ID numbers for consumers. The agencies reported frequent delays in assignment of employer ID numbers by the federal Internal Revenue Service (IRS). When the counseling/fiscal agencies filed tax forms without these ID numbers, they would receive complaints about the omission from a different IRS office. In addition, the IRS issued duplicate employer ID numbers to one consumer. The bookkeeper spent considerable time correcting this situation. Despite these initial problems, the two counseling/fiscal agencies submitted the payroll tax forms on time.

However, problems arose regarding timely submission of tax forms by the Area Agency on Aging (AAA), or by the consumers it served, before it dropped out as the demonstration's third counseling/fiscal agency. The counseling/fiscal agency that assumed the responsibilities of this AAA reported that the consumers it had served received notices that state and federal payroll taxes had not been paid for their workers. In addition, state unemployment insurance forms had not been submitted.⁹ While it took some time for the second counseling/fiscal agency to negotiate a resolution of these problems with the various state and federal offices, it was able to do so. No consumer participating in IndependentChoices was penalized for delayed submission of tax forms.

One lesson from this experience is the importance of a clear transition if one counseling/fiscal agency takes over from another. Such a transition would ensure that the second agency does not inherit problems from the first.

⁹ These problems may have arisen in part because about 25 consumers had been listed on the AAA's records as managing the cash benefit themselves when they were not doing so in practice. After the AAA dropped out, these 25 consumers chose to have the counseling/fiscal agency manage the cash benefit for them and were pleased with this arrangement.

Nonetheless, in the process of resolving the problems arising from delayed submission of tax forms and unemployment insurance forms, the counseling/fiscal agency established good working relationships with contacts in each of the relevant state and federal offices. These relationships proved useful in the long run, as they made it easy for either party to get questions answered and issues resolved. For example, this counseling/fiscal agency was able to negotiate annual (rather than monthly) filing of some state forms to avoid the need to submit payments of less than a dollar per consumer.

This counseling/fiscal agency recommended the early development of relationships with the state revenue office and the IRS regional office. Such relationships facilitate teaching contacts at the state and federal offices about the cash program and learning agency staff about state and federal requirements.

In spring 2000, a demonstration audit uncovered another problem with payroll taxes. Neither counseling/fiscal agency had properly refunded excess withholding when a worker earned less than the minimum required for federal tax liability. To prevent a repetition of these errors in future years, the certified public accountant employed by IndependentChoices and a consultant provided by the National Program Office developed a mechanism for refunding excess withholding and procedures to implement this mechanism.

D. Major Lessons on Cash Planning and Management

The major lessons of IndependentChoices with respect to cash planning and management are threefold. First, the Arkansas experience shows that it is feasible for most interested consumers--even those with limited formal education--to develop a cash plan within a period of a few weeks provided that (1) they have a counselor's assistance, and (2) can identify a worker from among their family members and friends. Counselors were needed to explain the program and to "pace" the process of developing a cash plan when consumers found it overwhelming. Written materials were useful only in conjunction with counselor visits. Those who had to look beyond family and friends to identify a worker to hire had a much more difficult time developing a cash plan and were more apt to disenroll from the cash program.

The second, and related, lesson is that cash planning and management can be labor intensive. Not only was counselor labor required for the development of cash management plans, but substantial additional counselor labor was required to revise care plans as consumer needs and desires changed, even when the initial care plan was written to provide flexibility. In addition, substantial additional effort was required of state staff to review nonroutine uses of the cash.

The third lesson is that counseling and fiscal issues are closely associated when it comes to cash management. Counselors and bookkeepers pointed out that consumer questions usually involved both counseling and fiscal issues: "Whichever came first--the other usually followed." Moreover, counselors had fiscal responsibilities; they reviewed timesheets and purchase orders to ensure that they conformed to cash management plans.

Both the Arkansas counseling/fiscal agencies believed that combining counseling and bookkeeping within one organization promoted efficient communication about cash management. However, the close association of counseling and fiscal issues does not necessarily imply that counselors and bookkeepers must communicate interactively. The counselors and bookkeeper of one of the Arkansas counseling/fiscal agencies established a close working relationship characterized by frequent give and take. At the other agency, however, the counselors were responsible for addressing both counseling and fiscal questions raised by consumers. There, the bookkeeper's role was limited to cutting checks to fulfill purchase orders completed by counselors. We will return to the question of the organizational structure of counseling and fiscal services after we have examined other aspects of the work of the counseling/fiscal agencies.

VII. REPRESENTATIVES

Slightly less than 50 percent of consumers participating in IndependentChoices had representatives to assist with the management of the cash benefit. Under IndependentChoices, the consumer chose the representative, who was to be in regular contact with the consumer. The representative could not be paid for helping with the management of the cash benefit and was not allowed to serve as a paid worker as well as a representative.

A. Selection of Representatives

The consumer decided (sometimes with the guidance of the enrollment nurses), whether to use a representative. As indicated in Chapter V, the enrollment process was designed to help consumers recognize whether a representative was needed. Typically, the consumers did recognize the need for a representative and identified that person during enrollment. Because the enrollment nurse requested that “the person who might help you make decisions” be present during the enrollment home visit, the potential representative usually participated in the discussion about the need for a representative.

The question of who to select as a representative was usually settled naturally. Those consumers who needed help with financial matters or other decisions usually had someone assisting them already. For example, many elderly women had never handled their financial affairs and already had assistance with paying bills, writing checks, and other routine financial matters. As part of the enrollment process, the enrollment nurse typically asked who had helped the consumer in the past and with which tasks they had helped, thereby identifying people already assisting with financial (and other) tasks. Typically, those helping with financial tasks were relatives.

It was not difficult to find representatives for almost all consumers who needed them. The availability of the bookkeeping service to manage payroll taxes and other expenses was a very attractive program feature for representatives, as it freed them of the responsibility for these tasks.

The selection of a representative was formalized by completion of a document describing the representative’s responsibilities. Both the consumer and the representative signed this document.

Although most representatives were selected soon after the consumer enrolled in the cash program, they could be selected at any point during the demonstration--whenever the need for one became clear--provided the consumer agreed. For example, if the

evaluation staff had difficulty conducting the baseline interview with a consumer, they notified the state office (which, in turn, alerted the counseling/fiscal entity) of the possible need for a representative. For other consumers, if the training process was progressing poorly, the counselor might initiate a discussion about the need for a representative. For example, if the cash management plan was not developing satisfactorily, the counselor might discuss with the consumer the possibility of naming a representative to help with the decisions.

If the enrollment nurse felt that a consumer might need a representative but had not decided to appoint one, she discussed her observation with the consumer: "I think you need a representative. How do you feel about that?" However, the consumer made the ultimate decision and could proceed without a representative if he or she determined to do so.

While a consumer who was able to manage his or her own services could name a representative, this happened rarely. Almost invariably, consumers named representatives only when they needed such assistance. For some consumers, however, the need for a representative decreased over time, as the consumers became more secure in their role as employers. A few of these consumers eventually took over management of the cash benefit from the representative.

Occasionally, there was a need to change representatives. This usually occurred because the consumer wanted a person initially named as representative to be a paid worker and had not realized that, under the rules of IndependentChoices, the same person could not be both a paid worker and a representative. In such a circumstance, another person might be designated as representative so that the person originally named as the representative could become a paid worker. In only a few cases were representatives changed because they were not acting in the interest of the consumer.

A special document--the change of representative form--was completed whenever the identity of the representative changed.

B. Representative Training and Assistance

When a consumer had a representative, both the consumer and representative received training from the counselor on managing the cash benefit. In addition, the counselors trained representatives about the demonstration's philosophy that "in consumer direction, the consumer decides." (In contrast, in the traditional program, both consumers and representatives may be accustomed to having nurses make the decisions.)

Counselors used several approaches to reinforce the lesson that the consumer decides. First, when a counselor became aware of a discrepancy between views of the

representative and of the consumer, the counselor reminded the representative of the demonstration philosophy. Second, counselors always spoke with the consumer, directing questions and comments to him or her, rather than to the representative. When the counselors met with a representative, the consumer was always present and participated in the discussion. Third, during monthly telephone calls to consumers, counselors asked whether they were satisfied with their representatives, as well as with their paid workers. They reminded consumers that they could change representatives if necessary.

Representatives helped consumers in two ways: (1) by providing information about the consumer to counselors, and (2) by training consumers about the cash program. Because representatives knew the condition and care needs of consumers, their participation in the development of the cash management plan was valuable. This participation helped ensure that all relevant issues were discussed during the development of the plan--even those that might be sensitive (such as incontinence). Representatives helped counselors train consumers by further explaining issues that consumers did not understand during a counselor visit, reinforcing information between counselor contacts, answering consumer questions, and reminding consumers about the procedures of the cash program.

C. Major Lessons

One lesson from IndependentChoices is that many consumers needed a representative to help them manage a cash benefit. About half of the participants in Arkansas had a representative, and counselors felt that few of those with representatives would have been capable of managing the benefit without assistance.

A major lesson of IndependentChoices is that the representative selection process can be a natural extension of the relationships that consumers already have when they join the program and of the assistance they are already receiving. There was no need in Arkansas for a formal process to determine the need for a representative or to identify one. Almost invariably, consumers who needed a representative were already receiving help with financial matters, such as assistance paying bills and managing a checking account. Such consumers readily recognized their need for assistance with managing the cash benefit and agreed to the selection of a representative. Those who had been providing financial assistance--almost always relatives--simply assumed the role of representative as an extension of the assistance they had been providing. The availability of fiscal intermediary services (at no charge to the consumer) may have eased this transition by limiting the duties expected of the representative.

Another major lesson from IndependentChoices is that representatives almost always acted in the best interest of consumers. Counselors reported that representatives typically helped only with those tasks or decisions with which the consumers needed help. Usually,

the representatives appeared to be representing a *shared* viewpoint--that of the family, including the representative, and the consumer--rather than only the consumer's viewpoint. However, when there was any disagreement between the viewpoint of the representative and of the consumer, the representative generally supported the consumer's position, consistent with the philosophy of consumer direction.

In the counselors' view, representatives worked best when they were close relatives of the consumer. They reported that such relatives tended to take a holistic approach to the consumer's situation and needs and to act as advocates for the consumer. Close relatives also have a vested interest in seeing that consumers are having their needs met. Counselors viewed friends as satisfactory representatives for consumers who did not have a family member available to fill that role. However, according to the counselors, friends tended to take a more narrow view of the role of the representative.

Perhaps the ultimate testimony to the success of the use of representatives in IndependentChoices is that only a few consumers have actually fired their representatives. Most consumers had no difficulty in identifying a satisfactory representative, and those whose initial choice proved problematic felt empowered to change their representative.

VIII. CONSUMERS AS EMPLOYERS

For the great majority of consumers who hired workers under IndependentChoices, the success of consumer direction depended on the consumer's ability to be a good employer--that is, to make good decisions about recruiting, hiring, training, supervising, and (if necessary) firing workers.¹⁰ Unlike the bookkeeping functions, these tasks could not be delegated to the counseling/fiscal agency. The counselors were responsible for training consumers (and representatives) on how to hire, train, supervise, and fire workers, but not for performing these tasks for consumers. The counselors were also responsible for fiscal training for those consumers who wanted to manage the cash benefit without the assistance of the bookkeeping services. The counselors were the primary source of assistance to consumers in their role as employers; other types of support were relatively limited.

In this chapter, we discuss counselor training of consumers and representatives in employer responsibilities, beginning with nonfiscal responsibilities. We then consider other types of support offered by IndependentChoices to help consumers fulfill their role as employers.

A. Counselor Training on Employer Responsibilities

The counselors began training consumers to be employers at the first counseling visit. Consumers who expected to hire a worker were encouraged to write a job description, outlining what the worker's responsibilities would be. The counselors discussed the importance of the consumer having clear expectations and communicating his or her wishes to the worker. Particularly when a family member was to be the worker, the counselor emphasized that the consumer was the boss, that the "job" was to be taken seriously, and that the worker's performance would be monitored.

All consumers who planned to hire a worker received this basic training about employer responsibilities. Additional training might be provided later, depending on the consumer's needs and circumstances and his or her desire for additional training. This additional training on various tasks of the employer is described next.

¹⁰ For brevity, we generally do not distinguish between consumers and their representatives with respect to fulfilling the responsibilities of an employer.

1. Recruiting Workers

Although most consumers with family members knew which of these relatives was likely to be a good worker and which was not, consumers sometimes needed help sorting this out. In such cases, the counselor might say, "I'm sure your daughter would want to help out of love for you, but does she have the time to do it?"

If a consumer did not have a relative available to be a worker, the counselors took a phased approach to the recruiting process to avoid overwhelming the consumer. "We have them visualize a circle around them and say we want to start close, working outward, widening the circle slowly as we need to. So we start thinking about friends or neighbors, then perhaps someone in church, then someone a relative or friend knows." If all else failed, the counselors discussed how to recruit, interview, and hire a stranger. Consumers could have placed ads in the paper, but no one had done that by the time of our visit to Arkansas, perhaps because one of the major attractions of the cash program was avoiding having strangers in the home.

Consumers had to interview potential workers previously unknown to them. The counselors helped consumers think about how to conduct the interview and helped them practice interviewing. On occasion, counselors supported consumers by being present during the interview of a potential worker. Counselors also discussed with consumers how to follow up on references and the advisability of background checks and how to obtain such checks. (Arkansas did not require background checks, however.)

Hiring a worker could take a long time. In such cases, counselors were in frequent telephone contact with the consumer until a worker had been hired.

Despite all the efforts of counselors, some consumers were unable to hire a worker. The inability to do so was reportedly a major reason for dropping out of the demonstration before receiving the cash benefit.

2. Hiring, Supervising, and Firing Workers

Counselors in IndependentChoices frequently helped with the initial paperwork involved in hiring workers. The consumer-training manual for the cash program included the forms (including tax forms) required for hiring a worker. The manual also included a contract form for the consumer and worker to complete and sign to indicate their mutual understanding of the work agreement.

The counselors trained the consumer on how to supervise the worker. This included training consumers to tell workers clearly what was wanted and to give workers feedback about their performance from time to time.

During monthly monitoring calls, counselors asked about consumers' satisfaction with their workers' performance. By doing so, the counselors reinforced the right of the consumer to insist on satisfactory work from their employees and to make changes if necessary.

Most cases in which a worker was terminated were handled quietly within the family on the grounds that "the arrangement was not working out." Often, several family members would discuss the situation and agree on the best way to proceed. Another family member might assume the worker's responsibilities. Counselors supported these efforts. In a few cases, however, consumers fired their workers. In these cases, counselors supported consumers, giving them suggestions about how to proceed and helping them rehearse how to fire a worker. Sometimes, especially when there was no representative available to help, counselors were present to support a consumer who was firing a worker. Counselors did not fire workers, although they did report, "Sometimes they [consumers] want *you* to do it."

B. Training Consumers to Manage the Cash Benefit

Under IndependentChoices, consumers could elect to manage the cash benefit without assistance from the bookkeeping service provided by the counseling/fiscal agency. (These bookkeeping services were provided at no additional charge to the consumers.) The counselors were responsible for training those consumers who elected to manage the cash benefit themselves. The National Program Office hired a consultant to develop a manual for this purpose, which each state adapted to its own circumstances.

At the time of our visits in the spring of 2000, few consumers in IndependentChoices were managing the cash benefit themselves, and none who had hired workers were doing so.¹¹ Counselors reported, "We don't deny anyone the opportunity [to manage the cash benefit themselves]. If they want to try, we help them. We train them and find some local support for them if we can." Case Example VIII.1 relates the story of one consumer who tried to manage his own payroll without the assistance of the bookkeeping service.

Consumers who were managing the cash benefit themselves were required to keep receipts and use the cash according to the cash plan. Counselors monitored them to ensure that they were doing so. Counselors reviewed receipts during visits or asked consumers to send in copies of receipts for their review. The counseling/fiscal agency

¹¹ Approximately 25 consumers served by the Area Agency on Aging (AAA) counseling/fiscal agency had been listed as managing their own cash benefit. However, they apparently were not actually withholding and paying taxes and insurance. After the AAA withdrew, the counselors of the counseling/fiscal agency now serving their area discussed changing to the bookkeeping service with these consumers and all of them decided to do so.

maintained a financial chart for consumers who were managing the benefit, with copies of receipts for their program expenses.

Case Example VIII.1: Managing Payroll

Concerning a consumer who tried to manage his own payroll, the counselor reported, "He messed it up in two months. I worked with him and did some more training. He tried it for one more month and then decided to use the bookkeeping service. He said, 'This is not worth it.'"

The counselors reported that, frequently, consumers were initially intimidated by the paperwork involved in the cash program. Over time, however, several of them asked more questions, then decided to handle more tasks on their own. In addition, six consumers who had disenrolled because they were overwhelmed initially had reenrolled. According to the counselors, "Now they feel ready for it." The counselors were pleased to see these consumers gain confidence and believed that more consumers would become ready over time to take on more functions, perhaps including their own payroll.

C. Registries and Peer Support

Early in the demonstration, the National Program Office initiated discussions about two approaches that counseling/fiscal agencies might use to help consumers in their role as employers. These two approaches were worker registries and peer support groups.

1. Worker Registry

At the time of implementation of IndependentChoices, there was no worker registry or other formal resource to which a counselor could refer a consumer trying to identify a potential worker. Arkansas and the other states participating in the Cash and Counseling Demonstration had not established registries because they were concerned about possible liability if a serious problem should arise involving a worker hired through a registry.

In one area of Arkansas, however, an informal resource developed over time. A small number of workers expressed their interest in working for other consumers in the cash program, and the counseling/fiscal agency in that area began to maintain a list of their names. Counselors began to give the names of these workers to consumers having difficulty identifying a relative or friend as a worker. In doing so, the counselors made clear that the program was not making any judgment about the worker's qualifications and encouraged the consumer to follow up on the worker's references. In at least one case, a consumer did hire a worker this way.

A different situation illustrates another resource that might help consumers who have not been able to identify a worker. A woman who had been a worker for her relative until the relative's death volunteered to help other consumers on a temporary basis until they could find a worker.

Would such informal sources of worker referral improve the program for people without family or friends available to be workers? Although there have been no problems with this mechanism so far, there is as yet too little experience to draw a conclusion.

2. Peer Support

The National Program Office also encouraged counseling/fiscal agencies to establish peer support programs. At the time of our visit to Arkansas, neither counseling/fiscal agency had done so, citing transportation in rural areas as particularly difficult.

One agency, however, was developing a peer network. It had identified four consumers who had given permission to have their names listed in the IndependentChoices newsletter, with a note saying they were willing to take calls for questions. The agency was also trying to recruit some workers to do the same thing.

D. Major Lessons

The major lesson concerning consumers as employers in IndependentChoices is that many consumers satisfactorily fulfilled the nonfiscal responsibilities of employers (recruiting, hiring, training, supervising, and firing) and that counselor training played a major role in this success. A counselor described the major lesson learned about teaching consumers to be employers: "You have to be careful. They get frustrated with the decision-making process. We have to be patient, give them time. The education and training process of consumers, through visits and calls, is essential." Counselor training was also critical in stressing that the consumer was boss. Most consumers hired relatives or friends. While some critics of the cash program were concerned that it would prove difficult for consumers to exercise authority over workers who were relatives or friends, this was not the case. With counselor training, this potential problem was largely avoided in Arkansas. Consumers and workers--even close relatives--learned the philosophy of consumer direction from counselors.

Almost all consumers in IndependentChoices chose to split the employer *fiscal* responsibilities between themselves and the bookkeeping service offered by the counseling/fiscal agency--with the consumers retaining responsibility for completion of time sheets and the bookkeeping service assuming responsibility for filing state and federal tax returns and related documents. Consumers successfully completed the fiscal responsibilities that they chose for themselves. Few failed to submit time sheets promptly.

Is there cause for concern because consumers in IndependentChoices almost invariably elected to use the bookkeeping service for tax form preparation? Does their use of this service suggest a lost opportunity for further counselor training to foster independence? One disability advocate expressed concern that this might be the case. He argued that some consumers who have never been independent might be unaware of how far they could go and settle for hiring their own worker and using the bookkeeping service.

This concern seems misplaced. Consumers were assisted in taking responsibility for their fiscal affairs if they wished to try to do so. Moreover, the general public often chooses to pay experts rather than prepare their own tax forms. Surely, we should not expect more of participants in the cash program.

A final lesson of IndependentChoices is that the employer role was empowering for consumers. Under the cash program, a person who has depended on others is given authority. One counselor explained this empowerment process as follows: "I can see the light bulb go on for a consumer. 'Aha! I can be the boss! This can work!'" Advanced age is not necessarily an impediment to such empowerment. The same counselor reported the empowerment of a consumer who was 93 years old. This consumer lived in a small town where almost everyone had been called on to help her before. Under IndependentChoices, she became the boss.

IX. MONITORING TO PREVENT ABUSE AND EXPLOITATION

The possibility that consumers would be exploited or the cash benefit abused was a major concern of all involved in the Cash and Counseling Demonstration. Even so, those involved were sensitive to the fact that extensive control and oversight is inconsistent with consumer direction. Consumers must have the freedom to make choices and manage on their own, even if others would sometimes view their decisions as misguided.

Under IndependentChoices, three methods were employed to monitor the uses of cash and the consumer's condition: (1) contact between consumers and counselors, (2) review of receipts by counselors, and (3) review of the monthly financial statements by consumers. In this chapter, we describe the use of these three monitoring mechanisms and the lack of evidence of material exploitation and abuse of the cash program in Arkansas.

A. Contact Between Consumers and Counselors

Counselors and consumers were in contact by telephone and in person. Some contact was routine, while some focused on identifying and resolving problems.

1. Mode and Frequency of Contact

Originally, IndependentChoices required that counselors contact consumers once a month by telephone, visit them quarterly, and reassess them semiannually. Over time, some of these requirements were relaxed, and a more individualized approach to counselor/consumer contact was adopted, with the mode and frequency of contact depending on the consumer's needs. For most situations, monthly telephone contact proved adequate (representatives were also contacted monthly by telephone), and quarterly visits proved unnecessary. In a minority of situations, however, frequent visits were needed and quarterly visits were insufficient. Accordingly, the quarterly visit requirement was eliminated; counselors scheduled visits when they believed one was needed. The only required visits were those for reassessment. For consumers participating in both ElderChoices and IndependentChoices, the reassessment requirement was reduced from semiannual visits to annual visits, consistent with a revision to state regulations on the frequency of reassessment for ElderChoices clients. For consumers *not* participating in ElderChoices, the requirement of semiannual reassessment visits was not changed.

Counselors made two types of visits to consumers: problem-solving visits and drop-in visits. They made problem-solving visits when a specific issue needed resolution. They arranged for a problem-solving meeting with the consumer, representative, or worker in response to a specific issue that the consumer or representative had raised or in response to the consumer's uses of cash.

Counselors made drop-in visits to monitor the condition of the consumer and the uses of cash--just as they would have used the quarterly visits. They often made a drop-in visit when they were in the area to see another consumer. Counselors felt it was more efficient to be able to make home visits when they were already nearby than to be required to do visits at set intervals.

While drop-in visits often were routine, counselors also made them as part of a program of increased monitoring to investigate suspected problems. If a problem was suspected, the frequency of telephone contact was increased and a drop-in visit would be made, and, at the larger counseling/fiscal agency, the consumer's name was added to a list of those discussed at every staff meeting. More intense monitoring continued until the problem was resolved.

If a problem was suspected, counselors sometimes called upon IndependentChoices outreach/enrollment nurses to visit a consumer. In addition, in such cases, counselors sometimes called upon ElderChoices nurses to make drop-in visits for consumers participating in that program as well as IndependentChoices.

Initially, outreach/enrollment nurses believed that they would be able to identify cases at enrollment in which there was the potential for exploitation or abuse so that the counseling staff could be notified of the possible problem and institute closer monitoring. In particular, they expected to be able to identify cases in which family members or friends were likely to exploit the consumer, either by not performing the agreed-upon tasks (worker) or not respecting the desires of the consumer (representative). Experience proved this incorrect, however. Case Example IX.1 describes one case in which the outreach/enrollment nurse was concerned about the potential for abuse, but the concern proved unfounded.

Case Example IX.1: Identification of the Potential for Abuse of the Consumer

One outreach/enrollment nurse reported that she was so concerned that a son who was to be hired as a worker would not perform the agreed-upon tasks that she secretly hoped the case would be randomly assigned to the control group. When the case was assigned to the treatment group, she reported her suspicions to the counselor so that the case could be monitored more closely. To the surprise and relief of the nurse, the son performed the tasks, and the consumer was very satisfied with his work.

The counselors reported that consumers initiated many contacts with them. Counselors estimated that 20 to 25 percent of consumers might call in a month, and all consumers occasionally initiated contact with counselors. Usually, the consumers had questions about the use of cash or about their monthly financial statements. Sometimes, they wanted to report on their progress with a task or just to talk. One consumer--fondly called "Auntie" by her counselor--called almost daily for a period of time.

Overall, the counselors felt that the level of contact between consumers and themselves had been appropriate. The counselors considered the revised approach to contact to be sufficient and felt they were aware of how consumers were faring under IndependentChoices.

2. Topics of Discussion Between Consumers and Counselors

During the routine monthly telephone contacts, counselors collected information from consumers, responded to their questions, and encouraged their decision making. The quarterly telephone calls were more extensive and structured at the larger of the counseling/fiscal agencies than at the smaller one. At the larger agency, counselors used a checklist to ensure that everyone always gathered the same information. The checklist included (1) whether the consumer's condition had changed and, if so, how; (2) whether the consumer knew the amount of the cash benefit and how it was being spent; (3) whether the cash plan continued to reflect how the consumer wanted to spend the cash benefit; (4) how satisfied the consumer was with the care provided by his or her worker(s); and (5) how satisfied the consumer was with the performance of the representative (if applicable). The counselors at both agencies addressed any questions the consumers might have, encouraged them to discuss any problems, and supported them in their decision making.

Counselors reported maintaining a high level of alertness, during all contacts with consumers and representatives, for indicators of possible exploitation of the consumer or abuse of the cash benefit. Counselors scrutinized the expressions and demeanor of the consumer, worker, and representative for any hint of irregularity.

B. Review of Receipts

IndependentChoices required receipts when the consumer received cash for a specific purpose specified in the cash management plan, but not for the 10 percent discretionary fund. For consumers who managed the cash benefit themselves, this requirement meant that receipts were required for all expenditures except for the discretionary fund. Counselors reviewed these receipts during the next home visit or asked consumers to send the receipts to the office of the counseling/fiscal agency for review. They reviewed the receipts carefully, comparing them to the cash management plan and questioning any expense that was unclear.

Arkansas consumers did not seem to have any trouble with the receipt requirement. Indeed, many seemed very proud of their record-keeping. Counselors reported that the consumers and their families assumed that they would be required to save receipts to demonstrate that they were being responsible with Medicaid money. Most consumers retained receipts for purchases with discretionary funds as well as for cash-plan specified purchases for which they had received cash. Case Example IX.2 attests to the care with which consumers maintained receipts.

Case Example IX.2: Careful Maintenance of Receipts

One counselor told this story: "I went to see an elderly consumer who lived many miles from the nearest tiny town--12 miles down a gravel road, 3 miles down a dirt one, and a walk down an embankment past a burnt out pickup truck. The lady lived there with her daughter in a very old house. I wasn't expecting much from them. But she had saved every receipt in a Tupperware container with dividers. Each receipt was coded to show how it related to the cash plan, and on each she had written a little narrative description of the benefit of the purchase. Participants really want to do everything right."

Counselors viewed requiring receipts as a way to help empower consumers and representatives to prevent abuse of the cash by others, say, by other family members. If an inappropriate use of the cash benefit was suggested, the consumer or representative could simply point out that he or she would be required to produce receipts and that those receipts would be checked against the approved uses in the cash management plan. The counseling/fiscal agencies recommended that any cash program require the consumers to save receipts to document the use of the cash.

C. Consumer Monthly Financial Statements

Each month, the bookkeeper sent the consumer a financial statement showing disbursements from his or her cash benefit account during that month. Counselors also received a copy of this statement.

Consumers used this financial statement to manage their benefit and to check the accuracy of the bookkeeper's work. They tracked their own expenses and knew their balances throughout the month. When the statements came, consumers compared their own balances with the balances on their financial statements. If they had questions about their statements, they called the counseling/fiscal agency.

The counselors reported that they might get fewer calls about the financial statement if it were in a more user-friendly format. The statement, generated by the Peachtree software, was apparently somewhat confusing.

D. No Abuse of the Cash Benefit by Consumers

Counselors reported no material abuse of the cash benefit by consumers purchasing nonapproved items. In Case Example IX.3, one counselor puts the situation in his own words.

Case Example IX.3: Reducing the Potential for Abuse of the Cash Benefit

“Are we going to have abuse? Yes. Is it going to be significant? No. We have to give them the freedom and they will make mistakes. We see the mistakes as a need for training. The mistakes are easily corrected, involve small amounts of money, and are not habitual. If you make developing the cash plan a big part of the initial training, then you cut the potential for abuse to a very small amount.”

On occasion, consumers purchased something not named in the cash management plan, but these purchases were invariably consistent with the goal of supporting the consumer’s independence. Counselors called consumers about expenses for items not covered in the plans and sometimes altered the cash plan to include the new item.

These calls also were an opportunity for counselors to teach consumers. During such calls, counselors usually asked whether the consumer thought the price of the item was fair and described sources for purchases where things cost less. “We’re not the money police--it’s their money. But we always ask ourselves, are they trained well enough? Are they being exploited?”

The counselors believed that adequate safeguards were in place to prevent abuse of the cash management plan by the consumer. They believed that both the emphasis on developing the cash management plan during the initial training and the requirement to document purchases with receipts prevented abuse.

Although those close to IndependentChoices reported no material abuse of the cash benefit, there were a few complaints from others, primarily staff of traditional providers. All such complaints were investigated, and none were substantiated. Some complaints involved instances in which a worker hired with the cash benefit used his or her wages to purchase consumer goods. For example, there was a report that a daughter (the worker) “just bought a car with her mother’s funds.” Of course, the worker is free to spend his or her wages as he or she thinks best.

E. Exploitation of Consumers

The number of complaints of possible exploitation of consumers was limited. The few such complaints were raised by external sources and by the IndependentChoices counselors themselves.

1. External Complaints

While few external reports of abuse or exploitation of consumers were received by the IndependentChoices program or the state, those received tended to be from staff of agencies serving consumers participating in both IndependentChoices and ElderChoices. In these cases, the agency had continued to provide homemaker services under ElderChoices after the consumer had hired family members with the cash benefit. The reports of exploitation indicated that family members took money but were not working as agreed, leaving the homemaker to take on the remaining tasks or leave the consumer in the lurch. In addition, ElderChoices nurses (who continued to supervise the homemakers and provide annual reassessments for ElderChoices) voiced complaints in a few cases, saying that consumers weren't receiving the same high-quality care provided by the agency.

All reports of abuse or exploitation that the program or state received were followed up immediately by an IndependentChoices counselor and, if it seemed advisable, also by a nurse employed by the state. The counselor (and nurse) transmitted their findings to the state program office.

No external report of abuse of the consumer or the cash program was substantiated. In a small number of cases, family members were not doing the work agreed upon. These cases were resolved by discussing the problem with the consumer and family member. In at least one case, the consumer "fired" her son and hired another family member instead. In another case of reported exploitation, the representative was in the hospital, and another family member had taken responsibility for the consumer's care. The investigators found no abuse, although they reported, "The house could have been more presentable." When the representative recovered and was able to resume that role, the situation was resolved.

At least some of the concerns about the quality of care under the cash program probably stem from the relatively high standards held by the staff of the traditional agencies. A nurse's views about cleanliness and order are likely to be stricter than those of family members who may have little education and live in a rural area with few amenities. Some of the family members might have benefitted from training in how to be efficient and effective caregivers to the elderly. That said, there is almost no evidence that exploitation threatened the well-being of consumers participating in the cash program.

2. Counselor Reports of Exploitation

The counselors themselves identified two situations they characterized as exploitation or potential exploitation of the consumer. A counselor described the case of exploitation as follows:

In one case, we couldn't get in touch with the consumer, weren't allowed to speak with her on the phone. Her daughter was her worker. We went to see her, and she had lost a lot of weight. Her demeanor was anxious. Things were missing from the home. We got an emergency disbursement to help her move in with a different family member in another city.

In the situation presented as "potential" exploitation, the consumer had a representative and the counselor thought the consumer wasn't being allowed an active enough role in managing the cash. The counselor thought there might be some fraudulent use of the cash benefit. The counselor reported this to the state office, and the state decided to give the consumer another chance. When a problem occurred again, the state required the consumer to change her representative or go back to traditional agency care. She chose another family member as her representative and continued in IndependentChoices. The adequacy of her care had not been at issue.

In summary, with the support of their counselors, consumers were able to manage their benefit without being exploited. The counselors were alert for any sign of irregularity. They also recognized that consumers would make mistakes and that these mistakes indicated a need for further training. For their part, the consumers were realistic in their assessment of which family members were reliable and helpful. Their life experience and the structure that the program created helped them to take on increasing responsibility and avoid undue risk.

The lesson counselors learned about monitoring to prevent exploitation of consumers is the importance of careful observation to look for subtle changes and a positive approach to correcting problems. This lesson is expressed in Case Example IX.4.

Case Example IX.4: Prevention of Exploitation of the Consumer

"Prevention is a constant thing. Always be aware. There could be physical changes, little emotional changes. We take the approach that we are here to solve situations; it's not an issue of blame."

X. LESSONS FROM ARKANSAS

A number of valuable lessons can be drawn from Arkansas' experience with the Cash and Counseling model. Arkansas sought to develop a viable, cost-neutral program. We first address the question of whether it was able to do so and, if so, how this was accomplished. Second, we briefly summarize the lessons from the implementation of particular components of IndependentChoices that we described in previous chapters, then draw lessons that cut across components about the basic structure of the Cash and Counseling model as it was developed in Arkansas. Finally, we address the value of the Cash and Counseling model relative to a model of consumer-directed care offering only a cash allowance, asking whether the counseling and fiscal services are beneficial. (A separate report will draw lessons from the experiences of all three states operating Cash and Counseling programs.)

A. Lessons About Developing a Viable, Cost-Neutral Program

Arkansas had three major goals in implementing the Cash and Counseling Demonstration. The first and second goals involved assessing whether a cash benefit program could work in the environment prevailing in that state. Could the program be implemented as planned and would consumers find it sufficiently attractive to enroll? Arkansas' third goal was that the cash program benefit individuals who had been poorly served under the traditional system. In addition, although cost *saving* was not a goal, the state wanted a budget-neutral program, and budget neutrality was required under the terms and conditions for the demonstration waiver.

Here we assess the extent to which Arkansas achieved the first two of these goals. Definitive answers as to whether Arkansas achieved its goal of serving those poorly served under the traditional system and analysis of the program's impact on costs must await the impact analyses based on Medicaid claims. We provide some information relevant to those analyses.

1. Was the Cash and Counseling Program Viable in Arkansas?

Arkansas largely succeeded in achieving its first and second goals: the state successfully implemented IndependentChoices. The state showed that a cash program--at least in the context of a demonstration--is administratively and politically workable there. To do so, the state successfully overcame opposition from traditional home care agencies and attracted a large numbers of consumers. It also avoided material abuse of the cash benefit and exploitation of consumers--either of which might have had serious, adverse consequences for the future of IndependentChoices.

a. Implementation Largely as Planned

IndependentChoices was generally implemented as planned. Its implementation did depart from the design in some respects (as is typical in a demonstration program), but nearly all of these departures were minor. Below, we review the implementation of each component of IndependentChoices, noting the few major departures from the design.

Outreach and Enrollment. Arkansas largely implemented the direct outreach process it had planned; however, the state was required to adjust its plans to cope with unforeseen events. Faced with a delay in obtaining waivers and thus unable to begin enrollment, Arkansas continued its community information campaign longer than originally planned. When the pace of enrollment proved to be much slower than had been hoped, Arkansas (with the assistance of other actors in the demonstration) responded by lengthening the enrollment period, reducing the size of the target sample for the evaluation, devoting a substantial amount of senior program staff time to marketing, and adopting some marketing initiatives that had not been planned initially.

Arkansas successfully implemented its plans for centralized review of eligibility for Medicaid personal assistance services (PAS) and for allowing consumers to assess their own appropriateness for IndependentChoices and select their own representatives.

In Arkansas, enrollment procedures were largely implemented as planned. However, the outreach/enrollment nurses were unable to handle as many cases on a weekly basis as originally anticipated. Arkansas responded mainly by honing the efficiency of its procedures for enrollment.

Most of the attractive and unattractive features of IndependentChoices were those anticipated--with one major exception. The cash program was perceived by program staff as less attractive to clients who were also receiving ElderChoices services because aides from that program would still be coming to clients' homes and because the cash benefit tended to be lower for those also in ElderChoices (an artifact of a defunct state policy). Failure to attract ElderChoices participants probably contributed to the difficulty that Arkansas experienced in meeting the sample size targets of the evaluation since a large minority (about a third) of PAS recipients also received ElderChoices services.

Cash Benefit, Counseling, and Fiscal Services. Cash benefit levels under IndependentChoices were developed as planned. Discounting was at the rates established during the design phase of the demonstration.

Counseling services were successfully implemented largely as planned. Most participants (or their representatives) were able, with the assistance of counselors, to develop cash management plans, hire workers, and successfully manage their own care without abuse of the cash benefit or exploitation of consumers. The counseling/fiscal

agencies successfully enforced the requirement that consumers present receipts. There were only minor departures from planned procedures for counseling services. Requirements for the frequency of monitoring were found to be overly strict and were relaxed. The length of the notice for termination of traditional services was reduced to limit the potential for staff members of traditional agencies to persuade consumers to reconsider participation in the cash program. While neither counseling/fiscal agency had proposed developing a formal worker registry, one began to maintain lists of names of potential workers for consumers who were having difficulty recruiting workers.

Many aspects of fiscal services were implemented as planned, but others were not, and one important fiscal need was not foreseen during planning. Consumers received their cash benefits promptly, with few errors, and workers received their pay promptly. On the other hand, discretionary disbursements were not limited initially to 10 percent of the benefit as the state intended, and the counseling/fiscal agencies did not properly refund excess withholding to workers and consumers. After the demonstration began, the state added a special fund to help the counseling/fiscal agencies respond to the emergency needs of consumers. The need for this fund had not been anticipated as the demonstration was planned.

b. Arkansas' Strategy with Respect to Traditional Agencies

Arkansas successfully implemented IndependentChoices despite determined opposition from traditional home care agencies. How did the state accomplish this?

Arkansas succeeded by sharply limiting the influence of traditional home care agencies at critical junctures. The state itself took control of outreach and enrollment. Nor did it rely on traditional home care agencies to provide counseling services. Rather, it developed a solicitation process that attracted nontraditional host organizations to provide these services.

The opposition of the agencies providing traditional services did somewhat adversely affect the implementation of IndependentChoices, however. Had it not been for their opposition, these agencies might have been a valuable source of referrals to the cash program, especially since they were advocates for the elderly as well as service providers. Moreover, their opposition led to the decision not to cash out ElderChoices. Finally, the staff of traditional agencies sometimes spread misinformation about participation in IndependentChoices, forcing enrollment and counseling staff to expend considerable effort trying to correct this misinformation. Sometimes their effort was in vain; some interested consumers apparently elected not to participate in IndependentChoices because they had been misled about the implications of participation for eligibility for means-tested programs and tax liability.

Another challenge lies ahead for Arkansas and IndependentChoices. As described in Chapter XI, Arkansas is planning to seek an ongoing program of Cash and Counseling. The effort to do so may revive the active opposition of the traditional agencies, especially if the state cashes out ElderChoices as well as PAS.

c. *Generating Enrollment*

As a result of the demonstration, Arkansas determined that the cash program was attractive to a sizable minority of consumers. The number of IndependentChoices participants in spring 2000 was roughly 10 to 15 percent of recipients of Medicaid PAS. While the percentage is smaller than anticipated before demonstration operations began, it represents a significant fraction of consumers, especially when one considers that enrollment often builds slowly in new programs. Some consumers dropped out after enrolling in the cash program (usually because they were unable to identify a worker to hire), but most made the cash program work for them. There are many heartwarming success stories and few complaints from cash recipients.

There are several possible reasons for the relative lack of success of IndependentChoices among consumers who could not identify a worker within their circle of family and friends. First, they did not realize one of the most attractive potential benefits of the cash program--avoiding having strangers come into the home. Second, the wages that cash recipients offered might not have been sufficient to attract workers who did not know the consumer personally. Consumers received a cash benefit of \$8.00 per discounted care plan hour. After accounting for the employer share of taxes and other employer expenses, they were unable to pay workers more than about \$7.25 an hour (unless they were willing to reduce the number of hours of care below the number in the discounted care plan). Third, Arkansas and its counseling/fiscal agencies did not develop formal referral mechanisms for potential workers (although informal referral mechanisms did begin to develop relatively late in the demonstration). Such mechanisms likely would have eased the process of finding a worker for those consumers who did not have a family member or friend available to hire.

d. *Avoiding Abuse and Exploitation*

In the beginning, proponents of the cash program feared that even a single, widely publicized instance of abuse of the cash benefit or of exploitation of a consumer could make it politically impossible to adopt an ongoing cash program. To date, however, there has been *no* material abuse of the cash benefit in Arkansas. Nor has substantial exploitation of consumers been detected under IndependentChoices. While traditional providers raised concerns about the safety and well-being of a few cash recipients, state investigations in every case concluded that these concerns were unfounded. Moreover, IndependentChoices staff members were able to resolve the handful of cases of possible

exploitation that they identified internally, and none of these incidents resulted in adverse publicity.

2. Value of Independent Choices for Those Not Served by the Traditional System

Arkansas' third goal for Independent Choices was to serve people who were poorly served by the traditional home care program. The state appears to have achieved this goal. Independent Choices appears to have tapped a labor source--family members and friends--for people who had been underserved by traditional agencies or who had gone without services, perhaps because they lived in rural areas or were dissatisfied with agency services.

3. What Factors May Have Affected Program Costs and Budget Neutrality?

Budget neutrality (over the course of the five-year demonstration) was one of the terms and conditions of the federal waiver, and Arkansas wanted Independent Choices be budget neutral. While this study cannot answer whether Independent Choices was budget neutral or describe its impact on public costs, it can draw some lessons about paying for counseling/fiscal services, discounting the case benefit, and assessment that should be helpful in designing budget-neutral Cash and Counseling programs.¹²

a. Paying or Counseling/Fiscal Services

One lesson from Independent Choices with respect to the cost of counseling services, is that an overall caseload of about 75 consumers to one counselor appears to be reasonable. Thus, the payment structure must be sufficient to support the cost of one counselor for each 75 consumers participating in the program.

The certified public accountant the state hired to advise the counseling/fiscal agencies judged that the cost to provide basic bookkeeping services alone was about \$70 to \$75 a month per consumer receiving the cash benefit. The monthly costs are substantial because, to satisfy federal requirements for payroll tax filings, each consumer must be treated as a minibusiness with separate records.

Based on the Arkansas experience, we can offer one major lesson about structuring payment for counseling/fiscal services. The need for counseling varies over time, and the amount needed varies across consumers. These variations have implications for the structure of payment for counseling. Some consumers require a number of weeks to

¹² Recall that the key distinction between budget neutrality and cost is that budget neutrality is assessed in terms of the monthly cost per person, while the number of person-months of service obviously also affects costs.

develop their cash management plans. During these weeks, they are not using bookkeeping services and may be using counseling services only sporadically. In this situation, a one-time payment for the development of the cash management plan would better link payment to effort.

In addition, a one-time payment for the development of the cash management plan could be less costly. Under the monthly fee structure, the cost to Arkansas was quite substantial for consumers who required several months to develop a cash plan. Moreover, the state incurred the cost of traditional services (if any) as well as the cost of the monthly fee until the cash plan was developed and the first cash benefit received.

b. What Issues Affect the Appropriate Discount Rate?

Arkansas developed provider-specific discount rates for traditional providers based on care plan and claims data for random samples of Medicaid PAS recipients. These rates were used to discount the care plans of current clients of traditional providers. Despite Arkansas' best efforts, we cannot be sure that this approach ensured that IndependentChoices was budget neutral.

Two major factors--both largely out of Arkansas' control--affect the appropriate discount rate for the initial cash benefit. First, the ratio of the cost of services received to the cost of services planned may change over time, which makes the appropriate discount rate a moving target. As the labor market tightened in the full-employment economy of the late 1990s, traditional agencies may have been less able than they had been even a few years earlier to hire enough aides to supply all planned hours of care. If care planning did not change accordingly, the ratio of the cost of services received to the cost of services planned may have been different during the late 1990s, when IndependentChoices was implemented, from what it was earlier when the discount rate was developed. Indeed, when we visited Arkansas, traditional agencies as a group were planning to ask the Arkansas state legislature for an increase in the hourly rate at which the state pays them, noting that the increase was necessary to enable them to compete for an adequate supply of workers in a full-employment economy.

Second, the appropriate discount rate may differ from the initial discount rate because the PAS recipients who actually participate in a cash program may differ systematically from the group(s) for whom the discount rate was developed (in this case, the general PAS population *before* the cash program began). That discount rate might not result in budget neutrality if PAS recipients with particular care plan and service use characteristics were more likely than others to participate in IndependentChoices, and these same characteristics were associated with higher or lower discount rates. PAS recipients who were underserved in a traditional program (including those not served at all) were one subgroup with a greater incentive to participate in IndependentChoices. The very fact that they were characterized as "underserved" indicates that they were perceived

as receiving a smaller fraction of needed care than the PAS population generally. Assuming this perception was correct, either the care plans of the underserved systematically understated their care needs or they received a smaller fraction of care plan hours, on average, than PAS recipients in general (or both). If they received a smaller fraction of care plan hours, a different discount rate would have been appropriate for the underserved.

In addition, ElderChoices recipients were reportedly less likely than other PAS recipients to participate in IndependentChoices. While the fraction of PAS care plan hours ElderChoices recipients received is unclear, they did have particular care plan characteristics, which may have been associated with their receiving a different fraction of care plan hours than PAS recipients in general. Their PAS care plans reportedly tended to call for fewer PAS hours, on average, than did those of other PAS recipients.

We cannot judge from the evidence at hand, however, whether a different discount rate was called for due to differential participation of these or other subgroups. We do not yet know whether the ratio of the cost of services received to the cost of services planned differed for these subgroups and PAS recipients in general. The examination of care plan data for control group members should help address this question.

c. *How Does Assessment Affect Program Costs?*

Another factor that may have affected program costs and hence budget neutrality for IndependentChoices is the possibility of differing assessment procedures for treatment and control group members who were new to PAS. Traditional agencies may have reassessed new recipients of PAS referred to the control group rather than honoring care plans developed by the IndependentChoices outreach/enrollment nurses. When demonstration participants were assigned to the control group, they received a letter from IndependentChoices notifying them of their assignment and encouraging them to contact the state program office if they needed a referral to a traditional home care agency. If the program office was involved in a referral for a recipient who was new to PAS, it forwarded a copy of the care plan developed by the IndependentChoices outreach/enrollment nurse to the agency that was to provide traditional services. However, the traditional agency was under no obligation to honor such care plans. If they did *not* honor them, the costs of the treatment and control groups could differ. In that case, the care received by control group members would have been based on the care plan developed by the traditional agency, while the amount of the cash benefit received by treatment group members was based on the care plan developed by the outreach/enrollment nurses.

Also, Arkansas' discount rate for the care plan following reassessment (commonly required every six months) for those who were already receiving PAS may have been insufficient to ensure budget neutrality. As planned, the state implemented different reassessment procedures for cash recipients and recipients of traditional services. These

differences may have implications for budget neutrality. The discount rate applied to care plans following reassessment for all cash recipients was 91 percent--substantially more generous, on average, than the initial discount rate for those who were already receiving PAS when they enrolled in IndependentChoices (these ranged from about 70 to 91 percent). This generous rate was applied to both routine and event-based reassessments and may have increased the amount of the cash benefit for consumers who were reassessed.

Moreover, counselors and traditional providers may have systematically differed in the number of hours of care planned following both regularly scheduled and event-based reassessments. Traditional providers, faced with a shortage of aides, may have avoided increases in the hours of care authorized even when an increase was justified. In contrast, counselors may have been more likely to authorize an increase in planned hours of care since the cash program was tapping a different supply of workers--the family members and friends of consumers. Moreover, with relatives and friends available as workers, counselors may have been more likely than traditional providers to conduct event-based reassessments.

Finally, because counselors were working closely with staff of IndependentChoices at the state level, they may have been more likely to seek authorization from the state Medicaid utilization review office to exceed the normal "cap" of 64 hours of care per month.

B. Lessons of IndependentChoices

In Chapters IV through IX, we presented major lessons from each component of IndependentChoices. Here, we summarize those lessons, then present other lessons that pertain to the structure of counseling/fiscal services and thus cut across components.

1. Summary of Component-Specific Lessons

a. Outreach and Enrollment

In Arkansas, direct mailings to recipients of Medicaid PAS appear to have been the most effective approach to generating enrollment in IndependentChoices. Direct mailings were more targeted and precisely worded than newspaper articles and public service announcements. State program staff considered direct mailings to be more cost-effective than the other two marketing techniques because fewer resources were expended responding to inquiries from those who proved ineligible for Medicaid PAS.

Clearly, direct marketing was much more effective in Arkansas in generating referrals than was the community information campaign (perhaps in part because of the opposition of traditional providers and the delay in implementing enrollment relative to the start of the

community information campaign). Also, Arkansas identified one promising venue for community information efforts--businesses, such as pharmacies, providing services for which the cash benefit was likely to be spent.

The Arkansas experience also suggests the importance of adequate staff time for community information and marketing efforts. Arkansas would have needed substantially more resources than were available to simultaneously implement its community information, marketing, and enrollment efforts.

Arkansas learned to make the enrollment process more efficient by reducing paperwork, smoothing work flow, minimizing travel, and reducing multiple home visits for a single case, almost to the point of eliminating multiple visits for enrollment. Having family members and friends present at the initial home visit was particularly important in minimizing the number of cases with multiple home visits; family members and friends were potential representatives and workers, and they could answer questions that consumers raised after the home visit.

Another important lesson about responding to consumer questions was to provide information in ways that people of limited reading ability could understand and to frame answers to their questions in terms that they found meaningful. Moreover, the state provided many opportunities for oral communication; written materials alone were insufficient.

Under IndependentChoices, program staff also faced an extra challenge. They needed to actively combat misunderstanding and misinformation that the cash benefit would be treated as income to the consumer for the purposes of determining eligibility for means-tested federal programs and for determining federal tax liability.

b. Cash Benefit, Counseling, and Fiscal Services

Three lessons emerge from the Arkansas experience with respect to cash planning and management. First, counseling for cash planning and management is labor intensive--both for development of initial cash management plans and for revision of cash plans as consumer needs and desires change. Second, counseling and fiscal issues are often closely associated. The issues that counselors address often have fiscal implications, and discussion of fiscal issues often reveals underlying counseling issues. (For example, during a call from a consumer about revising the cash management plan, the counselor might learn that the consumer is dissatisfied with a current worker's performance.) Third, most interested consumers--even those with limited formal education--can develop a cash management plan within a period of a few weeks, provided that they (1) have assistance from counselors, and (2) can identify a worker from among their family members and friends.

Many consumers in IndependentChoices needed a representative to help them manage the cash benefit. An important lesson of Arkansas' experience is that representation can succeed as a natural extension of the relationships that consumers already have and of the assistance they are already receiving. Under IndependentChoices, consumers who needed a representative generally identified that need themselves and selected the representative wisely. Representatives almost invariably acted in the best interest of consumers, with family members taking a holistic view of consumers' situations and acting as consumer advocates.

Except for difficulty in recruiting workers from beyond the circle of family members and friends, consumers satisfactorily fulfilled the nonfiscal responsibilities of employers (hiring, training, supervising, and firing). Counselor training of consumers played a major role in this success, partly by treating consumers as "the boss" and thereby empowering them relative to their representatives, workers, and other family members.

Under IndependentChoices, almost all consumers chose to split the fiscal responsibilities of an employer between themselves and the bookkeeping services that were provided without additional charge. On the whole, consumers successfully completed the fiscal responsibilities that they retained as employers, such as prompt submission of worker time sheets.

IndependentChoices presents two major lessons about monitoring to prevent abuse of the cash benefit and exploitation of consumers. First, requiring receipts to document the uses of cash seems to have been instrumental in preventing the abuse of the cash benefit because it empowered consumers and representatives to prevent family members from using the cash benefit inappropriately. Second, counselors' careful observation for subtle changes in consumer behavior and a positive approach to correcting problems were key ingredients in preventing almost all exploitation of consumers.

2. How Should Counseling and Fiscal Services Be Structured and Paid for?

Three important lessons about structuring a Cash and Counseling program can be gleaned from the Arkansas experience. These lessons pertain to (1) combining counseling and fiscal services, (2) having multiple counseling/fiscal agencies, and (3) orientation of the host organizations and staffing of the counseling function. We can also draw lessons from Arkansas' experience about structuring a payment schedule for counseling and fiscal services.

a. Combining Counseling and Fiscal Services

A hallmark of the structure of IndependentChoices was that counseling and fiscal services were combined. While bidders interested in becoming a counseling/fiscal

agency could propose subcontractors, the state required that a single entity be responsible for both counseling and fiscal services.

The state staff and the counseling/fiscal agencies believed that combining these functions was advantageous. The agencies argued that counseling and fiscal activities are so closely linked that combining them enhances efficiency. The state agreed and also mentioned efficiencies from limiting the number of organizations with which it had to interact.

On the other hand, some performance issues arose with respect to fiscal activities. While day-to-day bookkeeping activities went smoothly, neither of the counseling/fiscal agencies was fiscally sophisticated. Despite the technical assistance that the state and the National Program Office provided, both counseling/fiscal agencies erred in their handling of excess withholding and of cash disbursements. Perhaps these errors might have been avoided had the host organizations had more fiscal expertise. Possibly, organizations with more fiscal experience would have been interested in bidding if the counseling and fiscal functions had been separated, as the need for coordinating a joint bid and subcontracting would have been eliminated.

b. Value of Multiple Counseling/Fiscal Agencies

Another structural attribute of IndependentChoices was having multiple counseling/fiscal agencies serving different geographic areas of the state. Having multiple agencies was an important safety net for the cash program, enabling program operations to proceed smoothly at two critical junctures. These junctures were (1) when the state did not receive an acceptable bid for counseling/fiscal services in one area of Arkansas, and (2) when the successful bidder for another area dropped out of IndependentChoices early in the demonstration.

Simply having multiple agencies may not be enough to form a safety net, however. One or more of the existing agencies must be in a position to expand to cover other areas of the state. Geographically based organizations, such as an Area Agency on Aging (AAA), likely would have difficulty doing so. In this regard, Arkansas was perhaps fortunate to have a for-profit organization as one of its counseling/fiscal agencies. This agency had the flexibility to expand to provide counseling and fiscal services; ultimately, it was serving consumers in roughly three-quarters of the state.

c. Orientation of Host Organizations and Staffing of the Counseling Function

The orientation of host organizations may have been a fundamental strength underlying the successful implementation of the cash program in Arkansas. Neither host organization focused on providing case management nor traditional home care (although one did have a small Medicaid personal assistance program). One organization's

background was the provision of rehabilitation therapy--helping people regain independent physical functioning. The other organization provided a variety of services but at its heart was a school serving young children, some with physical disabilities. The underlying philosophies of these host organizations may have been naturally compatible with the philosophy of consumer direction.

The successful implementation of IndependentChoices may partly reflect how these host organizations structured the provision of counseling services. In each organization, counseling was provided primarily by full-time staff responsible only for IndependentChoices. Thus, counselors could focus their attention on implementing IndependentChoices without being distracted by other responsibilities. In addition, counselors shared caseloads, having found that the approach was more efficient (it reduced telephone tag with consumers and travel time) and more fully utilized the specialized expertise within the counseling staff.

Perhaps other structures and orientations would also have been successful. We have little evidence on this issue from Arkansas. However, its brief experience with an AAA as a host organization suggests difficulties with another orientation and another approach to structuring counseling services. The AAA's counselors were responsible for other programs as well as IndependentChoices. They continued to serve as case managers for the traditional home health/home care programs (the AAA's primary service program) at the same time that they served as counselors. Since the AAA remained in IndependentChoices only a brief time, we cannot know how its structure and orientation would have affected the provision of counseling services over time. But it is noteworthy that state staff were not satisfied with the counseling services provided by the AAA at the time it dropped out of IndependentChoices, believing its counselors to be overly prescriptive.

d. Cash Flow of Counseling and Fiscal Agencies

There may be a problem inherent in the payment structure that Arkansas adopted for counseling/fiscal agencies at the beginning of the demonstration. All of the counseling/fiscal agencies reported serious cash flow problems during the early weeks of operation of IndependentChoices. Because the counseling/fiscal agencies were paid on a per-participant-per-month basis, the agencies had relatively little cash flowing into the program until they had established reasonable caseloads. Yet they were required to hire counseling staff to help consumers develop cash management plans. The AAA cited financial issues as the reason that it withdrew from the cash program. Moreover, this cash flow problem may have discouraged other organizations from responding to the IndependentChoices solicitation.

A straightforward solution to this problem may be for the state to provide new counseling/fiscal agencies with an up-front payment before implementation of the cash

program. This payment could be recouped later, when an agency's caseload became large enough to sustain its operation.

C. Value of Counseling and Fiscal Services

Perhaps the fundamental tenet of the Cash and Counseling model--the tenet that distinguishes it from other models of consumer direction--is the provision of counseling and fiscal services to help consumers manage their cash benefits. Some critics of the Cash and Counseling model argue that an unfettered cash allowance would be preferable, on the grounds that such an allowance is more consistent with the philosophy of consumer direction than a program that imposes restrictions on, and monitors, the uses of the cash benefit. States, however, must balance this argument with the concern that state Medicaid funds might be misused, which could jeopardize political support for the program.

What can we learn from the Arkansas experience about the burden imposed by restrictions on the uses of cash and about the value of counseling and fiscal services to consumers?

1. Burden of Restrictions on Uses of Cash

The Arkansas experience suggests that consumers who participated did not find the restrictions on the use of cash troublesome in their everyday lives, although some declined to participate due to restrictions on the use of cash, particularly the state's decision to prohibit the hiring of spouses. IndependentChoices staff reported that few participating consumers complained about the restrictions on the cash benefit. Counselors appreciated the state's flexibility in allowing creative uses of the cash as long as the expenses pertained to the consumer's need for personal assistance. This flexibility likely worked to limit consumer complaints about restrictions on the use of cash.

Counselors reported that consumers seemed to accept the authority of the Medicaid program to impose restrictions on the use of public funds and expected to be asked to show receipts to document their adherence to these restrictions. Almost no one spent the cash benefit on inappropriate purchases.

2. Value of Fiscal Services

Clearly, the fiscal services that IndependentChoices provided were attractive to consumers. Consumers were not required to use these fiscal services, yet almost all did so. Only a few consumers chose to manage the cash benefit entirely on their own (although more consumers certainly might have done so had they been charged directly for use of fiscal services).

3. Value of Counseling Services

The value of counseling services to consumers is more difficult to assess than the value of fiscal services. In general, counselors seemed to contribute to a sense of empowerment among consumers, and counselor monitoring and a positive approach to problem solving seem to have been important in preventing exploitation of the consumer and abuse of the cash benefit. Nevertheless, consumers varied greatly in the amount of advice and training they needed from counselors. While some consumers needed little or no advice or training, others needed a great deal of assistance, especially in the weeks and months after enrollment as they developed a cash management plan and recruited workers. For the latter group of consumers, the advice of counselors seems to have been a valuable service. Initially, counselors tended to overwhelm such consumers with materials and information. Over time, however, they learned to focus on what consumers needed to know, offering to provide the details if consumers wanted them. Step by step, consumers appeared to learn to take more and more responsibility for managing their own care. Overall, counseling seems to have been very valuable--perhaps essential--to the success of the cash program in Arkansas.

XI. TOWARD AN ONGOING CASH PROGRAM IN ARKANSAS

Based on its experience with the Cash and Counseling Demonstration, Arkansas is working to adopt a version of IndependentChoices as an ongoing program.

A. Introduction

The ongoing cash program--which the state has given the working title of IndependentChoices II--would serve the same population groups as the demonstration program. That is, it would serve adults 65 years of age and older and younger adults with physical disabilities. It is possible, however, that Arkansas will adopt some version of a cash program for other population groups. For example, at the time of our visit, the state officials responsible for children with developmental disabilities were considering the development of a cash program for that population.

IndependentChoices II will require that the state obtain a waiver of Medicaid regulations from the Centers for Medicare & Medicaid Services and the Office of Management and Budget.¹³ The state is also considering seeking an amendment to its current waiver under the demonstration to allow members of the control group to receive a cash benefit. The features of a cash program under such an amendment would presumably be similar to those of the current demonstration program and are not discussed further here. Rather, in this chapter, we discuss the major differences that the state envisions between the design of IndependentChoices and that of IndependentChoices II.

B. Differences in Demonstration and Ongoing Programs

At the time of our visit in spring 2000, Arkansas envisioned five major differences between the design of the demonstration program and IndependentChoices II. First, outreach would not receive as much emphasis in the permanent program as in the demonstration. Freed of the need to build a caseload sufficient to support a rigorous evaluation, Arkansas would let the program grow at its own pace.

Second, the state would not hire nurses as outreach/enrollment staff in the ongoing program, as it did in the demonstration. State officials initially chose to hire nurses for two

¹³ We describe the revised cash program as “ongoing” rather than “permanent” because waivers are time-limited.

reasons: (1) they believed that nurses would make the program more acceptable to the community, and (2) outreach/enrollment staff were to be responsible for assessing the care needs of those interested in the cash program who were new to Medicaid personal assistance services (PAS). Based on their demonstration experience, state officials no longer believe that it is important to have nurses responsible for outreach and most aspects of enrollment. Under IndependentChoices II, the state would have nurses responsible for only one aspect of enrollment--assessment of those new to Medicaid PAS. At the time of our visit, Arkansas was considering contracting with fee-for-service nurses to conduct enrollment assessments.¹⁴

Third, Arkansas expected in spring 2000 that it would cash out its home- and community-based waiver program, ElderChoices, as well as its state plan Medicaid PAS, as part of an ongoing program. State officials believed that not cashing out ElderChoices made the cash program much less attractive to PAS recipients also enrolled in ElderChoices than to PAS recipients generally.

Fourth, under IndependentChoices II, state officials would place more emphasis on training consumers to be employers than they did in the demonstration program. They recognize that the informal, individualized training of the demonstration worked well overall. State officials envision enhancing that individualized approach by providing counselors and consumers with more tools. For example, the state was considering strengthening local resource directories to help counselors identify programs from which consumers might be able to obtain services free or at a reduced charge and sources offering goods at discounted prices. The state also envisioned developing a caregiving training program for paid workers; this training would be an option available to consumers at a fee.

Finally, state officials planned to change the structure used to pay agencies for delivering counseling and fiscal services. They were considering a single, one-time payment for assisting consumers in the development of the cash plan, rather than paying a monthly fee for every month the consumer is enrolled even if he or she has not yet developed a cash plan. This approach promises to be a major improvement in program financing, as it would better align payment with counseling/fiscal activity. In addition, state officials were considering changing the structure of monthly payments for ongoing counseling and fiscal services to eliminate the decrements in payment.¹⁵

¹⁴ Counseling/fiscal agencies became responsible for enrollment (for a one-time fee) effective July 2001. The state did not require that nurses conduct the assessments. This change was made when the contract for counseling/fiscal services was re-bid.

¹⁵ A one-time payment for development of the cash plan was implemented for the demonstration program in conjunction with re-bidding the contract for counseling/fiscal services. The decrements in monthly fees were also eliminated. These changes became effective July 2001.

Arkansas views a consumer-directed cash program as a valuable part of a package of Medicaid programs designed to meet the needs of its citizens. The revisions to IndependentChoices described above are intended to strengthen its cash program.

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APPENDIX A. Self-Screening Forms

Independent Choices Participant Self-Assessment

- I. **YOU DECIDE WHAT SERVICES AND PURCHASES WILL HELP YOU MEET YOUR PERSONAL CARE NEEDS.**
 1. **What services do you want and need?**

 2. **What purchases will help you?**

- II. **YOU SELECT THE PEOPLE YOU WANT TO HELP YOU OR WHAT THING YOU NEED TO BUY TO HELP YOU LIVE IN THE COMMUNITY.**
 1. **How will you find and select people to help you in your home?**

 2. **How do you shop for the purchases you need to make?**

3. How do you plan to train and supervise the people who work in your home?

4. How will you tell your workers what you like or don't like about their work?

5. If you are not happy with the work of the worker you hire, how will you handle the situation?

III. A COUNSELOR CAN HELP YOU LEARN HOW TO FIND YOUR WORKERS, HOW MUCH TO PAY YOUR WORKERS, HOW TO TRAIN YOUR WORKERS AND MANY OTHER THINGS.

1. Are you willing to ask for help if you need it?

_____ Yes

_____ No

IV. FAMILY OR FRIENDS CAN HELP YOU MAKE DECISIONS IF YOU WANT.

1. Do you have someone you want to appoint as your representative decision maker?

_____ Yes

_____ No

Independent Choices Representative Screening Questionnaire

Name of Participant: _____

Medicaid #: _____ Phone #: (_____) _____

Name of Proposed Representative: _____

Address: _____

Phone #: (_____) _____ Relationship: _____

If you are not a family member, please describe your relationship, how long you have known the participant and how often you have contact with the participant: _____

Do you receive money from the participant or anyone else to care for the participant? Yes: _____ No: _____

If yes, please identify the source and purpose of the funds?

After reading the description that outlines the responsibilities of the representative, do you understand your functions and are you willing to volunteer to serve as the participant's representative?

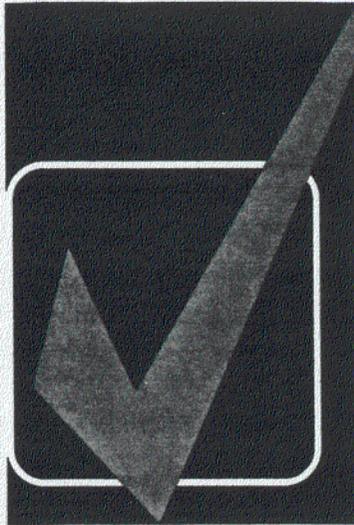
Yes: _____ No: _____

Are you willing to sign a designation form stating that you will serve in this capacity? Yes: _____ No: _____

Do you understand that you cannot pay yourself for this role and cannot become a paid caregiver? Yes: _____ No: _____

APPENDIX B. Show Cards

Independent Choices



*Division of Aging
and Adult Services*

Welcome!

**This information
will tell you more
about a new way
to obtain Personal
Care Services**

The Project will give you:

- *More Choices*
- *More Control*
- *Greater Flexibility*
- *More Responsibility*

1-888-682-0044

Division of Aging and Adult
Services

P.O. Box 1437 - Slot 1412
Little Rock, AR 72203-1437

Consumer Direction Means

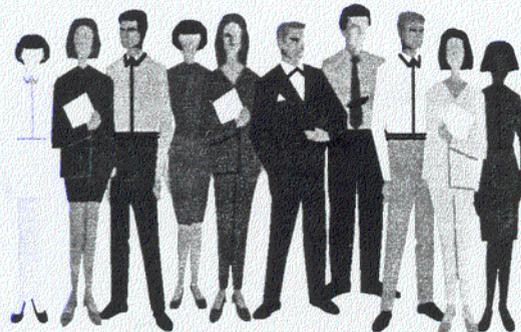
You Have a Say-so In -

**What Services You Receive
Who Provides Those Services
When They are Provided
How They are Provided**

**3,500 Arkansans will have the
opportunity to participate in this Project**

With

**1,750 Arkansans selected to receive a
cash allowance to help manage their
own personal care services**



Is Independent Choices Right For Me?

Only you and your family can decide

If you need help
managing your serv-
ices - a friend or
family member may
help you.



Participation is
Voluntary !

Any time you wish to return to regular services -
just call

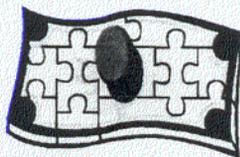
Only your Medicaid Personal Care Services Change

All other services remain just the same.

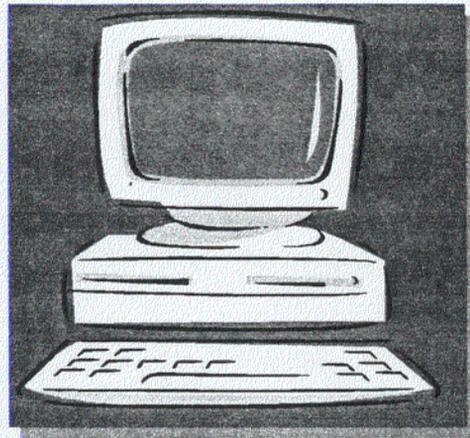
I Think I'm Interested Tell Me More!

Your participation is important!
You are helping us decide if this is a
good way to provide services.
We must have a way to measure
success in this experiment so
- we will have two groups -
one group will manage their own
services and receive the cash -
The other group will continue to
receive services from an agency.

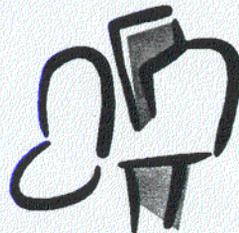
We compare both groups



If you are willing to help
us - your name will be
sent to a computer in
New Jersey

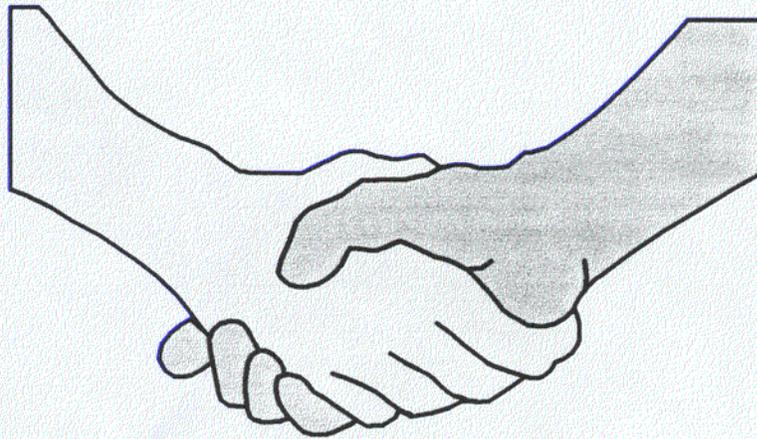


The computer will select
your name and tell us what
group you will be in



**Everyone
Selected to Receive the Cash Allowance
Will have a Counselor**

The Counselor is your partner



The Counselor -

- ✓ Offers Suggestions
- ✓ Helps with Problems
- ✓ Helps you become more Independent
- ✓ Visits you in your home
- ✓ Helps you plan your personal care services
- ✓ Offers Bookkeeping Activities
- ✓ Helps you Plan your Cash Expenditure Plan

The Cash Allowance

If I'm selected to receive
the Cash

How much will I receive?



Your monthly cash allowance is based on
the number of hours in your Personal
Care Plan
compared to
the number of hours of Personal Care
you actually receive in a month

You receive \$8.00 times this amount

A Division staff person will tell you how
much you can expect

If I Am Chosen to Receive the Cash Allowance How may I Spend It?

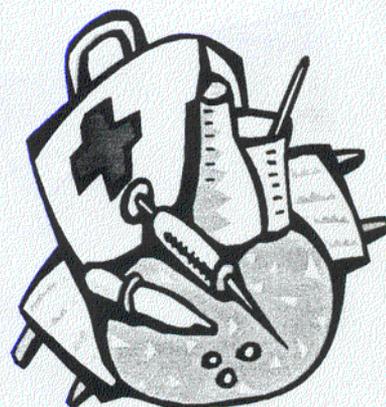
Hire someone to help you with
your personal care needs?

Perhaps a friend, neighbor or
relative?



Buy items related
to your personal care?

Buy Necessary Items Not
Covered by Public Funding?



Save for Some-
thing you need?



What Responsibilities do I Have If I Hire Someone?

You Will be the *"Employer"*

This means - you



Hire

Train

Supervise

Arrange to pay state &
federal taxes

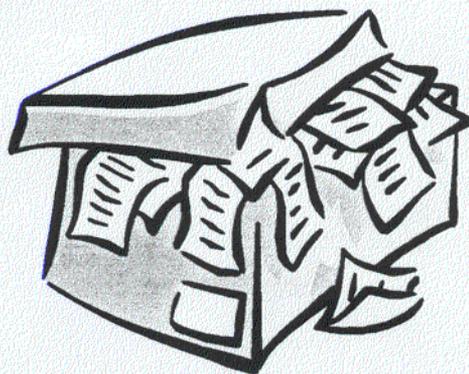
Remember - the
Counselor is there
to help you



Independent Choices Means You Have Responsibilities

◆ Keep Receipts:

Part of the study will identify
how the cash
allowance is spent



◆ Answer Questions:

Many people will
contact you and want to know what
you think about managing your own
services

◆ Work with the Counselor

Regular Home Visits
& Telephone Calls



Accounts You Choose



**Checking Account
Medicaid \$\$**

**Savings Account
Medicaid \$\$**

to

to

Counseling/Fiscal Agency

Counseling/Fiscal Agency



Agency

Agency



To your Bank

To your Bank

Or

Or

**The Agency Keeps
& makes your payments**

**The Agency Keeps
& you ask for it**

Does the thought of hiring someone and managing their payroll tasks sound too hard?

You have choices and

We're here

to help



Option I - *"Chose Option I - you pay-out the funds"*

Option II - *"Chose Option II - that's all done for you!"*

Your help is equally important Whether you're in the

Treatment



You receive
the Cash

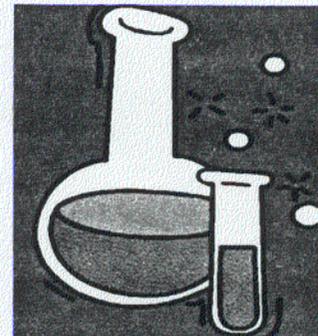
Control



The Aide
continues to come

Everyone will be contacted to see
what they think

Without both groups - we
Don't have an
experiment

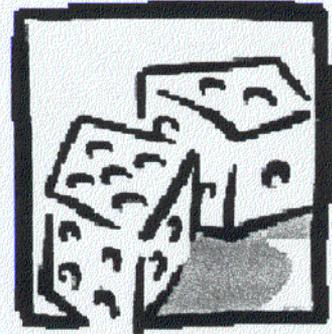


We Want You to Know

✓ This is a Scientific Experiment

✓ The Project will last for at least two years

✓ You have a 50/50 chance to receive the cash allowance



✓ You must follow all state and federal laws and regulations

We Want You to Know

- ✓ The Only Service Affected is Medicaid Personal Care
- ✓ All Other Services (including Medicare and Medicaid) Will Remain Unchanged
- ✓ This is a Voluntary Program
- ✓ You can Return to Agency Services at Any Time You Wish
- ✓ A Counselor will Help You by Providing Support and Advice

If I'm in the Control Group - Should I Be Disappointed?



NO!

**Your services may stay the
same
but you're opinions Count!**

We need to know what is good and not so good about both ways. You can help us by talking with us.

You are the key to our success!

Independent Choices Rights

If you Disagree with any Decision
You have the Right to Appeal

This includes:

Loss of Medicaid

Loss of Personal Care

Eligibility

Removal from the Project

Number of Personal Care

Hours

Sorry -

You cannot appeal your
selection into the Group
that does not receive
the Cash Allowance